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ABSTRACT

This final report describes the rationale, goals and activities of a federally funded project that was designed to develop a model intervention program for hospitalized chronically ill children between birth and five years. The focus of the program was to promote optimal emotional development: attachment, separation, individualization, and socialization. A multidisciplinary team consisting of a pediatrician, a psychologist, child development specialists and volunteers worked together with 46 children and their families. The children were provided with play activities, peer interactions, and a consistent daily caretaker. Parents joined as partners in working with their children, and hospital staff responded with enthusiasm, participation, and an increased number of referrals to the program. The program developed a curriculum with print materials, slides and videotapes for hospital personnel, covering the major areas of emotional and cognitive development, information on how to work with parents and siblings, and helpful approaches to commonly encountered problems. This report also includes a description of challenges encountered by the project, information about the study group at the beginning and end of the intervention, and a review of dissemination and continuation activities. Appendices include: (1) Project devised/adapted measures; (2) Presentations; and (3) Publications. (SG)

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Final Report

# Children in Hospitals A Model Program

UCLA Medical Center

Department of Pediatrics

Division of Child Development

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Grant# G008400789

CHAMP

**Children in Hospitals A Model Program**

**Funded by the U.S. Dept. of Education**

**Handicapped Children's Early Education Programs**

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## I RATIONALE AND DESCRIPTION OF PROGRAM SERVICES

During the past three years we have developed a Model Demonstration program for chronically ill hospitalized children under the auspices of the U.S.Department of Education. The rationale for our program was based on a recognition of the needs of this group of children, a perception that they are at high risk for developmental problems, and the observation that there were no programs available that addressed these issues. Our intervention services were closely linked to the rationale we set forth in the original grant proposal. A summary of that rationale and our program intervention follows.

Over the past 40 years, pediatrics has changed dramatically. Many life threatening diseases, particularly in the area of infectious disease, have been brought under control with the use of antibiotics, the development of vaccines and the wide spread availability of health care. More recently attention has been turned to other areas and significant progress has been made in BMT, TPN, renal dialysis, organ transplantation and cardiac surgery.

Expertise and technology in these fields sometimes results in a cure, but more often prolongs a life that is for from perfect from a medical, social and emotional standpoint. The children who benefit from the new technology are subjected to frequent hospitalizations and multiple medical procedures.

Since the early 1970's we've known that any hospitalization greater than one week, or repetitive hospitalizations, may result in a disturbance that does not terminate with the end of the hospital stay, but will tend to persist throughout life. Studies comparing the non-hospitalized child with children hospitalized one week or more show a higher incidence of behavioral problems, learning disabilities, and difficulties in forming healthy relationships in the hospitalized group. Although types of illnesses have changed and hospital practices have been altered since these reports, the same problems continue to exist. A look at the developing child gives us some idea of why hospitalization is traumatic for any child, and more strikingly so more if it occurs over and over again as with the chronically ill child.

While infants and young children are subjected to the same set of difficulties that illness inflicts upon any age (unexpected separations, unexplained physical pain, unfamiliar people and surroundings, frightening events, family disruptions, and depression), they are particularly vulnerable because of their developmental stage (Vernon, Foley, Sepowicz, and Schulman, 1965).

Children with chronic illness have the same emotional needs as healthy children but attainment of the major affective tasks of attachment, individuation and mastery (Erikson, 1950) is more complex. The task of the infant during the first year of life is to make a secure and selective attachment to consistent caretaker, usually his mother. The process requires a state of well-being in both infant and mother. It takes place during ordinary caretaking activities (feeding, changing and holding) while smiles, vocalizations and touches are contingently

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exchanged. As the infant grows, toys are introduces as an object of mutual interest between mother and child and the child begins to play.

With the acquisition of mobility, the toddler goes on to practice exploration of his world as a separate being -- hesitantly and for short periods with frequent reference to the attachment figure. Play becomes an important need for emotional and cognitive development. The child's play continues to be facilitated by, and often shared with the attachment figure.

As a preschooler, the child further expands his/her world, extending it to social relationships and developing associative play skills with other children. The attachment figure remains a reassuring support to be returned to with great frequency in difficult, new or threatening situations. In the ideal situation, the preschooler is becoming a trusting, autonomous being who can usually predict his environment, modify it a bit, and who feels secure and safe.

How does the chronically hospitalized child fare in the pursuit of these essential tasks, of childhood? In 1962, Provence and Lipton studied infants raised in an institutional environment during the first year of life. The care given to the infants was very routine and not individualized. Babies were "fed, diapered, and put to sleep on a schedule" that was "almost entirely externally determined." There were few contingency experiences for the infants. The infants were cared for at the convenience of the staff, irrespective of the infants' demands. Toys were available but were placed about the babies and not used as an object of shared interest. The babies were expected to play alone. At the end of a year, the infants were delayed or showed atypical behavior in the area of motor, social-emotional, and language development, and in the development of the object play. Hospitals as institutions often run on rigid schedules. As recently as the early 1980's a population of chronically ill infants living for much of the first year at UCLA were observed and similar motor delays and atypical behaviors were noted. They were depressed, disinterested in toys, and indiscriminant in smiling and vocalizations. Current studies by Thompson (1985) support older studies in demonstrating the persistent problems that emerge when the child's lack of contingency experiences interferes with emotional needs.

In addition to its impact on the infant, hospitalization also influences the mother's feelings of competence in her role as caregiver. In the same way that infants derive feelings of efficacy from mother-infant contingency experiences, the mother derives feelings of competence from contingency experiences provided by her infant. An infant who is weak or sick or depressed by being separated from the parents may be unable to respond in a positive manner to his mother when she visits. Or the infant may respond in a similar way to all caretakers without showing preference for the mother. Some young infants purposefully avoid eye-contact with the mother under the stressful circumstances of hospitalization. Any of these situations makes it difficult for the mother to continue to reach out to her infant and find that she actually continues to have an effective mothering role. While mothers are frequently encouraged to stay with their

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infants, many cannot do so because of ongoing family demands, long distance, or financial necessity. The infant is then abandoned for long periods. Her feelings in this situation would make it even more difficult to respond to her infant when she is with him.

Even after discharge, Schafer and Callendar showed that hospitalization changes the infants feeding, sleeping, and elimination pattern on return home for up to several weeks. A mother may feel she's a stranger to her own infant and a negative feedback system can result in longterm consequences.

Beyond the first year of life, the toddler and preschooler continue to have difficulty coping with the hospital setting. Although the normal toddler begins to move away from the attachment figure, during this time he/she needs a consistent figure to return to for reassurance. The separation and strange environment of the hospital is formidable. Just as the infant might appear depressed, the toddler is insecure, clinging, disinclined to explore, and unable to play creatively.

The hospitalized preschooler may regress in toilet training and self-help skills, have difficulty with socialization, associative play and trust (Willis, Elliot, and Jay, 1982). He may be unable to move confidently into new situations. Cognitive as well as social and emotional growth suffer if this continues for any length of time after the chronically ill child is discharged.

We have noted that families are frequently unwilling to allow their toddler and preschool child to participate in available community resources. Fear of infections, injury, over exertion, damage to necessary indwelling catheters are frequent reasons to keep the chronically ill children house-bound. Play with neighborhood children, regional center services, headstart and local public schools often are not utilized. The child falls even further behind in development of socialization, and individuation. Persistence of a disturbance that begins in the hospital is more likely to continue if the child comes from a stressed family or if the relationship of the child with the family is poor. It has been noted, for instance, that the way the parent responds to the child's clinging upon return from the hospital may determine whether the disturbance persists or is dissipated.

The children at UCLA whom we identified as being at risk for these problems come predominantly from four subspeciality services: Hematology, Gastroenterology, Cardiology, and Nephrology. I will describe the impact of chronic disease on the development of these specific groups of children.

Hematology/Oncology

This group is made up primarily of children with leukemia or solid tumors. Treatment includes chemotherapeutic drugs and radiation therapy. The children are subjected to repetitive traumatic procedures (lumbar puncture, bone marrow aspiration, and intravenous medications). In the event of relapse of the disease, bone marrow transplantation may be done with repetition of chemotherapy and radiation therapy and more

procedures. Indwelling catheters are often placed into veins for access for frequent blood tests and medication.

The child is kept in an isolation room away from all but a few family members and medical personnel caring for him. Isolation is sometimes required for months and interferes with their participation in play with other children. After successful transplant, activities and contacts remain restricted.

This group is often diagnosed during the second to fifth year of life and beyond. This is the age when the disease process and its treatment impacts primarily on the child's attainment of separation, individuation, and socialization. Particularly difficult for this group of children is the change in physical appearance (hair loss) that occurs with chemotherapy. Nausea, vomiting and weakness interfere with daily function. Nerve damage and central nervous system damage, which sometimes unavoidably results from therapy can have a long-term sensory motor and cognitive impact. The bone marrow transplant can have such a traumatic effect on a child that his development can come to a standstill.

For example, a twelve month old, developing normally at the time of the transplant, continued to develop in all areas except language, which remained at the same level for the next two years. With or without bone marrow transplant, the long-term care of these children is punctuated by periodic assessment with painful procedures, always with the possibility of relapse. Living with the threat of relapse is debilitating to both parent and child. They tend to approach life with a sense of vulnerability.

Gastroenterology

This group of infants and children include those who do not have a functional gastrointestinal system and have to be fed intravenously over an 8 to 12-hour period each day. With new techniques, these babies may be able to survive indefinitely without eating.

However, without oral intake, the attachment behaviors and the socialization that accompanies feeding is lost. These infants must stay in a sitting or lying position for long periods of time while the intravenous fluids run in. They have a permanent indwelling catheter attached to their abdomen or chest which discourages lying on their stomachs or creeping. They are often weak or malnourished for periods of time while an optimal level of nutrition is being worked out. Gross motor skills are almost inevitably delayed in these infants. Opportunity for play is restricted. Hospitalization is frequent and prolonged, sometimes occurring over much of the first year of life. When the babies are home, parents have an overwhelming responsibility in maintaining the indwelling catheter and delivering the intravenous fluids. Frequent infections, often life-threatening, and malfunction of equipment occurs. These children, as they grow, have a significant sense of life dependency on a machine. In their drawings of themselves, they include magnified versions of their catheters connected to the machine, with the machine drawn as an extension of their bodies. The

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development of a sense of independence and self sufficiency is a complex issue in these children.

Cardiology

This group is made up of an increasing number of infants and older children who undergo vascular or cardiac surgery early in life. Frequently a palliative, or temporary, procedure is done early, while the definitive repair is done when the child has grown. So they are often subjected to frequent long hospitalization for a series of surgeries as well as intervening assessments involving cardiac catheterization.

The parents of these children live with the uncertainty of the eventual outcome. Often the level of oxygenation in these infants and children is marginal. They are chronically short of breath. They have feeding difficulties because of the exertion needed to suck. Often they are gavage (tube) fed to save them energy. Deprivation of the feeding experience has an effect on attachment behavior as it does in the gastroenterology group. Even a short interaction with a cardiac baby might overtax him and result in cyanosis, so they are frequently left in relative isolation. Contributing to this is the oxygen tent which many of them require and which separates them even farther from the environment. These infants have little opportunity to play or practice gross motor skill, so they have frequent delays in these areas. As the children grow, parents are tremendously overprotective and fearful that they will overtax themselves. Often they will discourage the child from learning to walk and certainly prevent running and climbing. Toddlers with the skills to walk are sometimes wheeled for hours around the ward in baskets or wagons by a worried parent. Separation, individuation, and socialization for these children remains a difficult process. Unnecessary infantilization of these children contributes to their frequent delay in language, motor, and self help skills.

Nephrology

This is a group of children with end-stage renal disease. These children can now be maintained even in the early infancy period on peritoneal dialysis. This procedure requires an indwelling abdominal catheter and dependency either on a dialysis machine, or the use of a dialysis bag which can be taped to the abdominal wall.

Many of the same issues that arise for the gastroenterology and cardiac infants are present in this group. The infants are weak, have poor appetites, and fail to grow. The long periods of time spent on a machine and the attachment of the machine to a catheter in the abdominal wall makes placement of the infant in the prone position difficult. These infants have renal rickets with fragile bones that may break even with normal handling. This combination of problems results in gross motor delay and little play experience. Parents have to cope with lengthy hospitalizations and a poor long-term prognosis in their infants. This combined with the infant's weak response to caregivers and poor feeding skills, puts them at risk for attachment problems. Older children may be candidates for renal transplantation, may go home on chronic ambulatory peritoneal dialysis, or return to the hospital every other day for hemodialysis. These children continue to have bone

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disease and to be at risk for fractures. They complain chronically of "feeling sick" with specific reference to nausea and poor appetites. They have severe dietary restrictions in terms of water and salt and will go to great lengths to obtain forbidden foods and water. This behavior often results in another hospital admission. Children in this group who are maintained on chronic ambulatory peritoneal dialysis have more freedom from a machine and more time at home, but their parents must maintain complex equipment. Infection and malfunction are constant worries. Rickets, food restrictions, malaise, and indwelling catheters are factors that impinge upon the child's life, giving him little opportunity for independence and control.

So, in effect we have a new group of children, 1/4-1/3 of whom will not survive for the first 3 years of life. The rest of whom will be receiving intensive medical intervention, with varying amounts of time in the hospital from a few weeks a year to 12 months a year. Even when at home they and their families live with the tremendous burden of a new brand of chronic illness which in intensity is more like a continuous series of acute episodes rather than the background chronicity produced by some diseases. By the time they are 5 years old and ready for kindergarden these children who, if they had not had physical problems, would have been emotionally and cognitively in the mainstream, are no longer there.

How can we help this group of children? There are probably many approaches, none of which is a real solution but any of which might mitigate the emotional and cognitive impact of their disease.

Over the past 3 years we have tried one such approach on the Pediatric Ward at UCLA. Our intervention was targeted at children from birth to age 5. Funding allowed us to put together a multidisciplinary team with a pediatrician, a psychologist, child development (child-life) specialists and volunteers willing to spend 4 hours a day, 4 days a week with these children. Being at UCLA allowed us to draw from a much broader community of resources, including psychiatry, social work, and nursing service -- all working together to provide service for these families

Figure 1

**Staff**

**Pediatrician - Project Director**

**Psychologist - Evaluation/Assessment**

**Psychologist - Parent/Family Liaison**

**Child Development Specialists (3)**

**Individual Work with Children, Parents, and Siblings**

**Volunteers**

**Supervised in Individual Work by Child Development Specialists**

**Each Staff Member Involved in Grant Activities**

**1/3 Time - Funding for 2 Full Time Positions**



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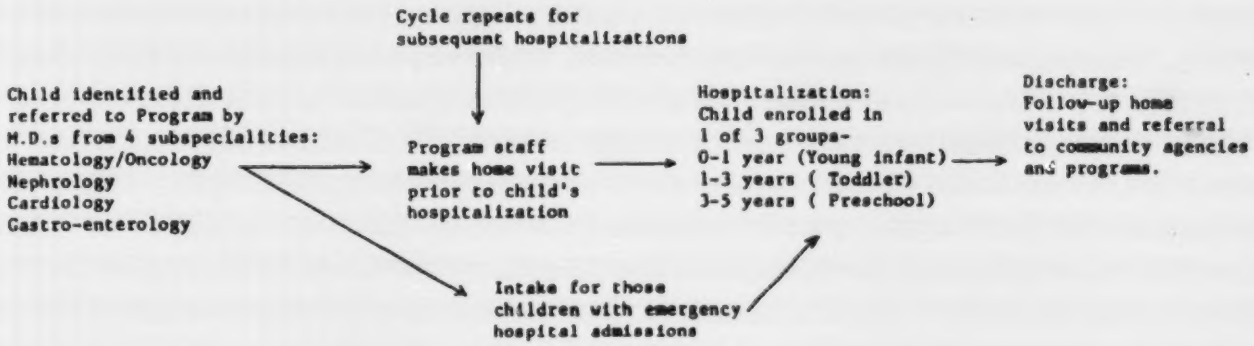
There are some aspects to our program which we feel are philosophically very important. Our primary focus is the emotional development of the child. We feel that the child's emotional needs must be addressed first before he can go on to other tasks. We work with the entire family, knowing that the impact of chronic illness is felt by every family member. Our intervention is continuous, whether the child is in the hospital or at home. The issues that we are addressing are long-term and do not dissipate when the child is discharged. Many of our goals are met through the establishment of a positive long-term relationship with the child and his family. Everyone, including the volunteers, have to be willing to commit significant time over the long range. This means functioning in a supportive role when parents can be present, and functioning in a parent surrogate role when they are unable to be present.

The program provides continuous intervention with referral into the cycle at any point, and movement around the cycle in synchrony with the child's hospitalizations. We like to start with children at home before their first hospitalization, but often we get them during an acute phase. Intervention before, during and after hospitalizations is focused on support and guidance for the child and his family with the aim of optimizing the child's ability to continue with his developmental tasks.

Figure 2


Cycle repeats for subsequent hospitalizations
Child identified and referred to Program by M.D.s from 4 subspecialities:
Hematology/Oncology
Nephrology
Cardiology
Gastro-enterology
Program staff makes home visit prior to child's hospitalization
Hospitalization: Child enrolled in 1 of 3 groups-
0-1 year (Young infant)
1-3 years ( Toddler)
3-5 years ( Preschool)
Discharge: Follow-up home visits and referral to community agencies and programs.
Intake for those children with emergency hospital admissions

Program Prior to Hospitalization

Initial contact with the family is made by the parent educator prior to hospitalization, and the family is invited to visit the pediatric unit. This telephone conversation provides the opportunity to discuss the parents' concerns and is part of the process for establishing a trusting relationship. A pre-admission visit (or several if necessary) allows the child to feel comfortable in the new medical environment through experiences which increase the child's familiarity with the setting child and family meet with a child development specialist, are taken through the unit, introduced to some of the staff, and given literature appropriate to their concerns. The child and siblings are encouraged to play in the playroom, ask questions and receive a play medical kit and a booklet about the hospital to take home.

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Figure 3

Pre Hospital Visit To Pediatric Ward

Staff

Child Development Specialists

Goals

Familiarize Family (Sibs, Parents, Child)
with Hospital and Staff Through Tour of
Play Room, Patient Room, Bathroom,
Kitchen, Doctors' and Nurses' Stations

Play Session with Option for Hospital Play
for Child and Siblings

Continue to Observe Interaction, Assess Needs,
and Answer Questions

Another aspect of the pre-hospital program is a home visit made by the psychologist and parent educator, which allows the family the opportunity to identify project staff who can offer support, guidance, and education. The staff is able to view the child and family in familiar surroundings and thus obtain valuable assessment information to plan the intervention program. Discussion centers around family concerns such as survival, preparation for procedures, siblings, developmental issues, and the hospital system. At the home visit, a videotape of the child and family is made to be used during the hospitalization to help the child recall family relationships, experiences, and skills previously enjoyed.

Figure 4

Pre - Hospital Home Visit

Staff

Pediatrician

Psychologist

Goals

Meet parents and child

Identify Needs

Chronic Needs

Short term needs during hospitalization

Address questions re: Hospitalization/Illness

Assess Child's Developmental level,
Parent/Child Interaction

Assess Parent's perception of child's condition,
understanding, prognosis, developmental level

Present UCLA Orientation information

Videotape child at play at home with family for
use during hospitalization

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In-hospital Program

The intervention program for the child in the hospital is defined by a number of components. The central element of the program is an Individualized Intervention Plan which builds on the strengths of the child to help the child adapt to the requirements of the hospitalization. Additional program services include parent group meetings, support for siblings, and specially trained volunteers. These aspects are discussed in the following sections.

Figure 5

**Hospital Program**

**Staff**

**All with introduction of volunteer**

**Goals**

**Admit child directly to playroom**

**Continue relationship with family**

**Address individual needs of family/child**

**Help parents maintain confidence in parenting their sick child**

**Facilitate child's maintenance of acquired developmental skills**

**Create environment in which developmental progress can continue**

**Continue assessment of family/child**

**Function as advocate for family**

**Give feedback to hospital staff**

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Individual Intervention Plan (IIP) An IIP is developed for each child in the program by the project staff in conjunction with the family. The IIP is written by the staff member, usually the child development specialist, who is most familiar with the child. Information is also based on the home visit, developmental assessments, and parental input. Issues addressed in the plan are the child's development in the affective areas of attachment, individuation, and socialization as well as the child's performance in adaptive behavior, language use, gross and fine motor skills, personal-social behavior, and self-help skills. The plan details the child's strengths an problems in each of these developmental areas.

Figure 6

**CHILD INDIVIDUAL INTERVENTION PLAN**

**NAME** _____ **B.D./AGE** _____ **DATE** _____

**Parent**_____ **Staff** _____

| STRENGTHS | PROBLEMS | OBJECTIVES | PROGRAM PLAN |
|---|---|---|---|
| | | | |

Assessment is basic to the IIP. The major purpose of the assessment is to understand the child and family in order to individualize and facilitate the intervention program. The focus is on the child's behavioral adjustment, and assessments and reassessments are done throughout the course of contacts with the family based on the status an needs of the child and family. Standardized instruments, interviews, and clinic clinical observations are used. The child's ability to engage in age-appropriate social roles is measured by the Functional Status questionnaire (Stein, Reissman, & Jessop, 1981). The child's social and emotional development is assessed by a rating scale of the child's interaction with the mother during our home observation (adapted from Clarke-Stewart, 1973), and the child's behavior during developmental testing (Bayley Infant Behavior Record, 1969). During hospitalization,

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weekly behavioral observation notes are made by the child development specialists. Written observations by volunteers are used also as part of the assessment. Cognitive development is measured by the Gesell Developmental Schedules. In addition, attitudes, concerns, and adjustment of the family are assessed through interviews and a questionnaire measuring parenting stress, (Abidin, 1983). This battery of assessments yields detailed information which is used as a diagnostic approach to direct our intervention.

Figure 7

**Assessment**

**3 Goals**

**Understanding the Child and His Family to Facilitate Intervention**

**Learning More About the Impact of Chronic Illness on Children and Families**

**Evaluating the Impact of Our Intervention**

**Instruments**

**Gesell**

**Bayley IBR**

**Peabody Picture Vocabulary Test**

**Parent Questionnaires**

**Parent Satisfaction Inventory**

**Intervention Program Record**

**Parenting Stress Index**

**Impact on Family**

**Functional Status Interview**

**Minnesota Child Development Inventory**

Creating a therapeutic environment is another essential part of our IIP. Making the patients's room more homelike and familiar increases comfort for the child and family. Parents are encouraged to bring the child's clothes, toys, transitional objects, stroller, and photos. The videotape made at the home visit is also used to help the child feel more at home in the hospital room. Based on the child's needs, a rocking chair, child-sized furniture, and floormat are provided. A cot is made available for the parent to stay with the child. Toys, music, and activities are used to enhance opportunities for control and mastery to maintain and increase developmental skills. A schedule for daily routines is determined and a schedule for the child development specialist and volunteer visits is posted in the room. Regular play sessions are provided in the child's room or playroom. The amount and quality of interaction and stimulation for the child is carefully monitored to avoid overstimulation.

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Figure 8

**CHILD ENVIRONMENT**

## CHILD INDIVIDUAL INTERVENTION PLAN

**Date:**

**Name:** _____ **B.D./Age:** _____ **Staff:** _____

| STRENGTHS | PROBLEMS | OBJECTIVES | PROGRAM PLAN |
|---|---|---|---|
| | Inherent to Hospital Environment: | Enhance Environment to: | Provide: |
| | Lack of homey familiar atmosphere | Increase comfort make home-like and familar. | Cot for Parent ___ Rocking Chair___<br>Photos from Home___ Infant gym mat___<br>Infant seat___ Mobile___ Walker___<br>Crib toys___ Musical toy___<br>Transitional object___ tape recorder___<br>Tapes___ Child sized table___<br>Small chair___ Shelves___<br>Record player & records___ books___<br>Art & craft materials___<br>Manipulative toys___ Dramatic play materials___<br>Wagon___ Kiddy Car___ Trike___<br>Wheelchair___ Child's name on door___<br>Stroller___<br>Parents available frequently yes___ no___<br>CDS assigned___<br>Vol assigned___ |
| | Noises, lighting, large numbers of strange people.<br>Intrusive and painful procedures are overstimulating, confusing and frightening.<br><br>Isolation Lack of consistent relationship with significant caregiver. | Provide a therapeutic balance in amount and quality of stimulation for child.<br><br>Ensure that child is supported by consistent relationship with parents, CDS, volunteers. | |
| | Lack of toys interfere with ability to play and continue to maintain Development skills. | Access to toys and activities for enjoyment and to continue opportunities to maintain and/or increase developmental skills. | Toys and activities to be provided on ongoing basis, based on child's needs.<br>Provide familiar toys from previous UCLA hospitalizations___ |
| | Lack of control: loss of mobility, predictability, sense of security and autonomy may lead to depression, aggressive behavior and or interference in ability to communicate. | Increase developmental skills.<br><br>Promote opportunities for control and mastery. Reduce confusion. Facilitate communication to help child to get needs met. | Schedule for Daily routine___<br>Calendar for wall___ Sign requesting - social visits be 10 minutes or longer<br>Schedule posted showing times volunteer will visit with child___<br>Communication aids___ |

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The Interventions incorporated into the IIP are based upon the child:s age and developmental level with attention to central emotional issues. These vary in the Infant, Toddler, and Preschool groups, but there is a great deal of overlap. Attachment for instance, is an important consideration for all hospitalized children. Often too, older children regress in the hospital setting and need to be approached at a younger level. The following program descriptions give general guidelines for different age groups.

Figure 9

Hospital Infant Program

Attachment is the Central Issue

Encourage parents to stay in hospital

Provide volunteer to act as surrogate parent and to support/relieve parent

Modify hospital room with Infant's toys, rocking chair, mobiles, nursery music, lowered hospital noise level

Activities based on baby's stress level, energy, state of well being

Position baby to optimize play opportunity, visual opportunity in spite of equipment or restraints

Use comforting techniques: rocking, singing, eye contact, and touch

Using baby's cues facilitate reciprocal social games, vocalization, smiling

Point out positive changes in infant's response

Support parents in in decision to be present or retreat from treatment procedure

Encourage parent to dress baby in clothing from home, bring their own stroller and equipment

Help parents become comfortable with machines and lines

Provide consistent daily visiting schedule with rituals that will become familiar to baby

Minimize number of casual visitors

Work with medical staff on initiating oral feeding in the older infant

Interpret child's and parent's emotional needs to hospital staff



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Figure 10

Hospital Toddler Program

Separation and Individuation are central issues.

Assure daily presence of parent and/or surrogate.

Facilitate maintenance and development of independent skills

Structure opportunities for choices and control.

Structure predictable daily events. Record pictorially on wall calendar.

Ritualize greetings and departures.

Provide corner table with age appropriate toys, music.

Encourage family to bring photographs and personal items of family, child.

Play video tape/voice recordings from home.

Help child learn the workings of the hospital environment - bed, sink, toilet, food trays.

Incorporate playroom activities into daily schedule providing hospital play and other play activities (music, tricycles, sand & water, playdoh, playhouse, guinea pig, celebrations).

Encourage play motivated approach to physical and occupational therapy.

Accept and interpret regressive, angry, difficult behavior to parents

Help parents with fair limit setting.

Work with child and staff on difficult issues such as medicine taking, procedures. Support and counsel parents in their decisions to participate or retreat.

Figure 11

Hospital Preschool Program

Socialization and mastery of independent skills are the central issues.

Encourage parents to stay in hospital.

Provide volunteer to act as surrogate parent and to support/relieve parent.

Structure predictable daily events. Depict on Wall Calendar

Provide opportunities in daily care to allow choices, participation and development of competency.

Set up corner table with child, letting him choose favorite activities/music.

Encourage child to dress in his own clothes.

Set up opportunities for play activities with other children in playroom.

Ritualize greetings and departures.

Use video tapes/audio tapes from home. Encourage photos and personal items.

Have absent parents, sibs call at same time of day.

Modify play environment to accomodate indwelling catheters, shunts, I.V. poles.

Organize small group activities - turntaking and games.

Encourage cooking and eating together, outings.

Provide materials for art projects. Allow child to decorate his room with products.

Encourage care taking activities with Guinea Pig.

Help parents allow activities to expand child's physical endurance as appropriate: Jumping, running and tricycle riding.

Bring activities to child's room if he is in isolation.

Structure play therapy sessions around medicine taking, procedures.

Prepare child for procedures with simple explanations, and play session shortly before event.

Interpret to parents child's level of cognitive understanding.

On the basis of the major strengths and problems, the staff formulates objectives and a program plan for implementation of the objectives in each area. Parent and sibling issues are also considered in the construction of the Individualized Intervention Plans and sections for other family members are included in the IIP. In order to illustrate the application of an IIP, a short case study and condensed IIP for a preschool aged child are presented.

## Case Study

Matthew, a 3 1/2 year old boy, and his family illustrate many of the issues the preschooler may face when dealing with chronic illness and hospitalization. Matthew was admitted to UCLA Medical Center for bone marrow transplantation for neuroblastoma, a form of childhood cancer. His mother, an ICU nurse in their home community, made plans to stay throughout the hospitalization. Relatives took care of the six year old brother in their home. Matthew's father planned his vacation to be with him in the hospital, but otherwise was able to visit only infrequently.

Matthew was referred to the CHAMP Program by hospital staff because of several concerns. He was so active they feared he needed medical intervention for hyperactivity. They were concerned that they would not be able to keep him in an isolation room, connected to I.V.'s and monitors. The staff noted a positive, caring mother - child relationship. The mother valued Matthew's independence and autonomy, and had difficulty setting limits. Developmental testing indicated that he was a competent child with a well developed sense of independence.

The staff began to work with Matthew and his family and the issues soon emerged. Matthew didn't feel safe. He was struggling to maintain the independent skills he had already mastered. He felt he had to be strong and active and in control because he felt so threatened. This sense of vulnerability was affected by two issues. First, his mother was so upset by Matthew's situation that it was impossible for her to provide the reassurance that consistency, firm limit setting, and age appropriate explanations would have allowed him. with all her nursing knowledge and awareness of the risks Matthew faced, she was in a terrible dilemma. She wondered if they had made the right decision in choosing the bone marrow transplant. Her fears and ambivalence were quickly picked up by Matthew. the second issue was that Matthew's verbal skills deceived others into expecting higher cognitive understanding than a three and one half year old possesses. The astute questions he asked were often given answers too rational or complicated for him to understand. When he asked where dinosaurs live, rather than being told they were extinct and didn't live anymore, he wanted to know that he was safe from harm. So Matthew armed himself with guns, knives and rubber alligators. He refused medicines despite his mother's desperate attempts to make them palatable and her logical explanations of their importance. He hit the physical therapist because she asked him, "Can you show me how strong you are?" Matthew was enraged and terrified when his mother tried to separate from him and so she rarely did, intensifying his fears that he wasn't safe because she didn't feel safe to leave him. To add to his difficulties the required isolation



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during treatment would limit Matthew's normal social interactions for an extended period. It would be a long time before many of the relationships and activities he had enjoyed before his hospitalization could be resumed.

The interventions were aimed at helping Matthew and his mother feel more secure. Regular sessions with the mother were arranged by the child development specialist. Matthew was seen daily for play therapy. In addition a volunteer was assigned and a schedule for her regular visits was developed. Matthew's mother began to allow herself daily breaks at the times the child development specialist or volunteer were with Matthew. The building of these relationships provided social interaction, opportunities to allay fears and model fair limit setting. Matthew responded to play sessions, exploring his feelings and concerns, and becoming more comfortable about medical treatments. He began to take his medicine with much less difficulty. He did remain active and maintained his independent skills. When they were discharged from the hospital after successful treatment, Matthew and his mother left feeling that they had mastered a difficult time. Their behavior showed that they were looking forward to renewing their life at home and in their community.

Matthew's intervention plan is partially reproduced in the following pages.

Figure 12

**INDIVIDUAL INTERVENTION PLAN** — **EMOTIONAL**

Name: Matthew Age: 3-1/2 years

| STRENGTHS | PROBLEMS | OBJECTIVES | PLAN |
|---|---|---|---|
| Responsive/playful | Anxious about own well-being | To decrease feelings of anxiety<br>To create a more predictable environment | Provide regular play therapy sessions to provide emotional release and mastery around issues dealing with his illness, hospitalization, and lack of security<br>Help staff to view Matthew's behavior as anxiety rather than as non-compliance or aggression<br>Establish predictable daily routines by pictorial calendar<br>Help staff to give mother clear cues to anticipate forthcoming events |
| Resilient | Anxious about procedures | To increase his tolerance of procedures | Prepare Matthew through play sessions by giving opportunities to enact difficult procedures<br>Help Matthew to develop strategies to cope with treatments and procedures, e.g. thinking about something pleasant, seeking emotional support, protest by "ouch"<br>Inform Matthew of progress during procedures<br>Interact with Matthew after procedure |
| Well developed sense of independence | Behavior problems around medication taking | To increase compliance | Encourage staff to be low-key in approach<br>Develop consistent approach for mother and staff to use regarding medicine gaking<br>1. Matthew given choice of method when choice available, e.g. medicine in cherry syrup or apple sauce, etc., 1 choice given<br>2. Nurse to give medicine with mother present to praise and support Matthew. Mother or nurse not to threaten mother's departure if Matthew doesn't comply<br>3. Matter-of-fact approach to avoid prolonging medicine taking, secondary gains and manipulation of situation by Matthew. Attention given after medicines are taken |

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Figure 13

**INDIVIDUAL INTERVENTION PLAN** **PARENT**

Name: Matthew Age: 3-1/2 years

| STRENGTHS | PROBLEMS | OBJECTIVES | PLAN |
|---|---|---|---|
| Mother able to to stay at hospital and sleep in room | Mother has difficulty dealing effectively with Matthew around separation | Mother and Matthew to feel more comfortable with separation | Work out plan with mother for separation<br>1. Matthew to be told when mother is leaving<br>2. Matthew to be told when mother will return using Matthew's pictorial schedule<br>3. Mother is to leave without prolonging separation; this is to be modeled for mother<br>4. Arrange for consistent staff/volunteer to be with Matthew when mother leaves |
| Mother has confidence in child's verbal/ cognitive skills | Mother's explanations above child's cognitive level | To increase mother's awareness of Matthew's level of comprehension | Help mother to be aware of child's level of understanding<br>Help mother to ask Matthew questions<br>Help mother to answer Matthew's questions on his developmental level by modeling and discussions with mother<br>Help mother to observe Matthew's response to events and conversations |
| Mother's knowledgeable about hospital environment, medicine | Mother's anxiety heightened by by her nursing | To reduce/ alleviate stress | Provide ongoing discussions with mother<br>Listen carefully to mother's concerns<br>Facilitate communication with medical staff<br>Build upon mother's suggestions regarding daily care routines<br>Encourage mother to perform routine care and mother is not to be given medical care of child |

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Parents are offered support through respite care and frequent contacts with the project staff. Discussions are focused on family problems and parent-child interactions. An important aspect of services offered to the parents is regularly scheduled parent meetings held two mornings a week on the pediatrics ward. The specific goal of the meeting is to help parents reduce their feelings of isolation and uniqueness. The meetings are led by a parent educator with a background in child development. The opening topic of the meetings is selected by the leader and is directed toward issues of dealing with the hospital staff, hospitalization, or a more general issue in child development. The format of the meeting is flexible and the discussion usually moves away from the opening topic and becomes centered on the parents' worries and feelings. Common topics include concerns for their child: ways to accept all the gifts and extra attention showered on the sick child; how to help grieving grandparents; how to nurture children at home who are missing their parent and ill sibling in hospital. Rarely do parents acknowledge or understand the toll on themselves of the constant strain during their child's long hospitalization, and often the meetings allow the parent to express their guilt, anger, fears and anxieties. The parent meetings provide and forum for sharing those reactions and feelings and for understanding the effects of hospitalization. The parents build a support system, and a network for friendship while in the hospital, and some of the stress of isolation is lessened.

Figure 14

**Hospital Program For Parents**

**Many Interactions with Parents are Focused on the Child and His Needs**

**Parent's Needs are also Addressed**

- **Supportive Counselling**
- **Psychiatry Available UCLA and Community**
- **Social Services Work on Transportation, Housing, Telephone Service, Respite Care**
- **Parent's Group**
  - **Led by Our Psychologist**
  - **Meets Twice a Week Over Coffee and Cookies**
  - **Mutual Support**
  - **Open Lines of Communication**
  - **Forum for Complaints/Sharing of Techniques in Working the System/Sharing in Successes in Working with Their Children**

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Siblings are also included in the intervention services. Families are encouraged to bring siblings during the pre-hospital visit and also during the hospitalization when appropriate. Individual play therapy sessions are offered to the siblings. Videotapes, audiotapes and pictures are exchanged and phone calls are facilitated between the children at home and the child in the hospital. Common sibling reactions are discussed and parents are helped to respond appropriately to behavior changes and questions the children raise.

Figure 15

**Hospital Program For Siblings**

**Visiting Encouraged**

**Exchange of Video/Audio Tapes and Pictures**

**Family Counselling Sessions**

**Play Therapy Sessions for Sibs**

**Make Parents Aware of "Normalcy" of Sibs' Reactions. Help Parents Respond Appropriately to Behavior Changes, Questions.**

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Volunteers are an integral part of our intervention program. They help provide consistent companionship, assist children in developing and maintaining skills, offer respite for the parents, and help the children and families feel more comfortable. Volunteer participation is intensive and consists of three hours per day three or four times a week. The volunteers are carefully selected and must demonstrate experience and sensitivity with children and families. Training begins before contact with the families and weekly training sessions are given for the volunteers to learn about child development and issues for hospitalized children. A child development specialist meets daily with the volunteers to supervise the sessions and assist in writing observations for project children. The observations are designed to document the child's progress, to note any problems, and to describe techniques that are successful.

Figure 16

**Volunteers**

**Important Aspect of Our Program**

**Criteria**

**Provide Continuity for Infants and Children by Donating 4 Hours 4 days a Week Minimum while Child Hospitalized**

**Demonstrate Sensitivity to Children and Families**

**Willing to Learn about Child Development and Issues for Hospitalized Children**

**Experience with Children Helpful**

**Ability to Cope with Hospital Setting Necessary**

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Post-Hospital Program

Our intervention continues after the child goes home from the hospital. Assistance is provided for the transition home and parents are encouraged to allow their child to engage in normal activities. Often parents are inclined to keep their chronically ill children housebound due to their fear of infection spread by other children, injury, over-exertion, or damage to necessary indwelling catheter or other equipment. In such isolation, the children fall behind in the development of individuation and socialization. When appropriate, referrals are made to community agencies such as child care programs, nursery schools, and regional center programs. Continued developmental follow-up with discussions on emotional and cognitive developmental issues is provided through further home visits and telephone consultations. Follow-up play sessions on the pediatric unit or at home are offered by the child development specialists. Children have a chance to work through some of their experiences and problems related to their hospitalizations, with the help of a person with whom they are already familiar. When future hospitalizations are scheduled, the child and family are invited to visit the ward again and become familiar once more with the environment.

Figure 17

**Post Hospital Program**

**Staff**

**All**

**Goals**

**Maintain Relationship with Family, Continuing Appropriate Services**

**Assist Transition Home**

**Help Parents Allow Normal Activities of Childhood**

**Make Referrals and Help Parents Enroll in "Mommy and Me" Classes, Regional Center Programs, Nursery Schools, Public Schools as Appropriate**

**Continue Developmental Follow-Up with Guidance on Emotional and Cognitive Developmental Issues**

**Contacts**

**Return Clinic Visits**

**Telephone Calls**

**Home Visits Every 3 - 6 Months**

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## II. GOALS AND OBJECTIVES

The goals and objectives set forth in our grant proposal are as follows:

IV. Goals

A. To develop a model intervention program for hospitalized chronically ill children between birth and five years and their parents in order to optimized their development through promoting attachment, separation, individuation, and socialization behaviors.

B. To develop a curriculum for hospital personnel that will provide experiences for the chronically ill children which promote attachment, separation, individuation and socialization.

V. Objectives

A. The objectives to meet goal #1, which is to develop a model intervention program for hospitalized chronically ill children are focused on the children, parents and hospital staff.

1. Children

a. To provide each hospitalized child with a consistent daily caretaker (parent and/or surrogate parent) sensitive to the child's needs.

b. To provide play activities during the child's hospital stay based upon the assessment of the child's developmental level.

c. To provide peer interactions that will introduce and maintain socialization experiences for the hospitalized child.

2. Parents - to develop a partnership with the parents, assisting them in gaining confidence in planning for their child's total needs based on their awareness and expectations.

3. Hospital Staff - to increase hospital staff awareness of the hospitalized chronically ill child's developmental needs.

B. The objective to meet goal #2 which is to develop a curriculum for hospital personnel that will provide appropriate affective experiences for the ill children will be accomplished by several means -- an edited videotape, a slide presentation with an auditory track, and a manual which will describe the process required for hospitalized children to develop appropriate affective skills as well as meeting their total developmental needs.

We have been able to meet the previously stated goals. Our model demonstration program was established with a focus on emotional development: attachment, separation individualization and socialization. Through our program activities and observations of the children's activities, we were able to develop a curriculum which we continue to use with our hospitalized children.

Our objectives have also been met fairly well. Play activities, peer interactions, and a consistent daily caretaker were major objectives which we provided to children without difficulty. A number of other inpatient strategies were developed as well. Parents responded to our efforts and joined as partners in working with their children. The hospital staff became acutely aware of the chronically ill child's needs and responded with enthusiasm, participation and an increase in referrals to our program.

We developed a curriculum for hospital personnel working with chronically ill children. A copy of the manual which is in press is attached. In the manual, we suggest that work with children begin with their strengths. Then we describe approaches to problems which we have found useful. We cover major areas of emotional and cognitive development as well as work with parents and siblings.

In addition we have developed slides and videotapes of the program in action. One such presentation was recorded on audiotape. We have presented our material to a number of groups and have found that varying our material is more useful and instructive than having a standard tape and slide show. A copy of the audiotape, video tape, and prints of our slides are available on request.

III. PROBLEMS ENCOUNTERED:

1. We encountered some problems and reaped some benefits in establishing this program in an already existing setting. The benefits included supplies, experienced personnel, a known population of children and facilities which were already in place. The problems were encountered when we tried to alter an already established status quo. Resistance was overcome primarily by the excitement that grew as we realized what a wonderful opportunity we had to do something for these children. We enjoyed sharing our expertise and presenting our ideas. The issue of setting up an intensive program such as this one in an already existing setting is important from the standpoint of replication. The cost was much more affordable under these circumstances.

2. We were unable to take a control group. This makes showing the effect of intervention much more difficult. There was a problem both of cost and of service provision. We don't deny services to any children in the chronically hospitalized group at UCLA. All children fortunately get some services though they are quite variable. It would be difficult to control the variability unless we included them in our study groups and carefully controlled the type and quality. This would have been prohibitive from a cost standpoint. We thought of following a low service group at another institution but again setting up a second study group would have been too costly.

3. We had some difficulty in patient selection. We wanted to take children who lived within 50 miles of Los Angeles to make home visiting and follow up possible. However, often the most needy children came from longer distances. These were the children whose parents could not stay or visit frequently. In our effort to be responsive both to the children and to the referring staff we took this group and sacrificed parent interviews, questionnaires, and home visits on this segment of children.

4. Initially we had difficulty recruiting children, but the nurses and subspeciality services were receptive and eventually referred more than we could take. We did staff education which we will continue.

5. The use of volunteers was an important aspect of our program from the standpoint of enriching the interactions and from the standpoint of providing a great deal of free service. We are fortunate at UCLA to have a large volunteer pool to draw from and were able to get high quality individuals who were able to commit themselves. From the standpoint of replication, in this aspect of the program would be more difficult in a non-academic center.

## IV. DESCRIPTION OF STUDY GROUP - RESULTS

The intervention study population consisted of 46 children and their families. Table I presents the description of the sample at the time of referral. The children ranged in age from 1 to 68 months. Referrals came from four services (cardiology, gastroenterology, hematology/oncology, and renal) and the percentage of the sample from each service is shown in Table I. The children were typically very sick at the time of referral. Many children were referred prior to a major hospitalization and others began their participation in the study during their hospitalization. The overall health status at time of referral was calculated on several parameters as follows: life functioning scale (adapted by the project from Karnovsky scale, see Appendix); prognosis at beginning of the project (a project devised measure, see Appendix); and growth status (below 5th percentile on any single growth parameter of height, weight, or head circumference using National Center for Health Statistics percentiles).

Table I

DESCRIPTION OF SAMPLE

| | Mean | Range |
|---|---|---|
| Age - months | 42 | 1-68 |
| Social class | 31 | 11-58 |
| % Boys | 59 | |
| % First born | 46 | |
| % Intact families | 65 | |
| % English speaking | 72 | |
| % Native born | 65 | |
| % Live within area | 50 | |
| Referral Service | | |
| % Cardiac | 30 | |
| % Gastroenterology | 30 | |
| % Hematology/Oncology | 26 | |
| % Renal | 13 | |

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The health status at both the beginning and end of the project is presented in Tables II and III. It can be seen that this is a very sick group of children, most of whom have a questionable or bad prognosis, score low on a life activity scale, and are delayed in their growth parameters. The health status did not improve significantly during the project for the group. Approximately 10% of the children showed significant progress, whereas twelve children died during the course of the project. Many of the children spent more than 3 months in the hospital during the project and were hospitalized repeatedly. One project child was in the hospital for 18 months, until his death, and received intervention services daily throughout this time.

Table II

HEALTH STATUS AT BEGINNING OF PROJECT

| | Prognosis | | | Life Activity Scale Mean | % Normal Growth |
|---|---|---|---|---|---|
| | % Good | % Questionable | % Bad | | |
| Cardiac | 21 | 71 | 7 | 59 | 43 |
| Gastroenterology | 7 | 50 | 43 | 37 | 29 |
| Hematology/Oncology | 0 | 58 | 42 | 35 | 42 |
| Renal | 0 | 83 | 17 | 52 | 33 |
| Overall | 9 | 63 | 28 | 45 | 37 |

Table III

HEALTH STATUS AT END OF PROJECT

| | Prognosis | | | Life Activity Scale Mean | % Normal Growth |
|---|---|---|---|---|---|
| | % Good | % Questionable | % Bad | | |
| Cardiac | 29 | 57 | 14 | 71 | 64 |
| Gastroenterology | 7 | 43 | 50 | 48 | 50 |
| Hematology/Oncology | 0 | 33 | 67 | 42 | 42 |
| Renal | 0 | 67 | 33 | 58 | 17 |
| Overall | 11 | 48 | 41 | 55 | 48 |

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Cognitive Status:

The children were tested reapeatedly during the project with the Gesell Developmental Schedules. Final testing of the older children (48 months or more), who were functioning within the average or above range, was done with the Peabody Picture Vocabulary Test. The children, as a group, were functioning within the low normal range. See Table IV. Thirty nine per cent of the group scored below 80 at final testing and 29% scored above 100. A few children improved dramatically in their cognitive development during the project, but the majority of the children at final testing scored within 15 points of their original project score. Thus, in spite of their severe illness, most of the children were able to progress consistently in their development. Three children decreased drastically in their development as their disease progressed rapidly.

Table IV

DEVELOPMENTAL FUNCTIONING

| | First Testing | | | | Last Testing | | | |
|---|---|---|---|---|---|---|---|---|
| | N | Mean | S.D. | Range | N | Mean | S.D. | Range |
| Cardiac | 13 | 87 | 26 | 35-126 | 9 | 95 | 17 | 64-11 |
| Gastroenterology | 14 | 90 | 19 | 54-118 | 8 | 78 | 29 | 38-12 |
| Hematology/Oncology | 11 | 93 | 13 | 71-119 | 7 | 85 | 15 | 64-10 |
| Renal | 5 | 75 | 36 | 22-113 | 4 | 74 | 45 | 27-12 |
| Overall | 43 | 88 | 22 | 22-126 | 28 | 83 | 26 | 27-12 |

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Figure 18

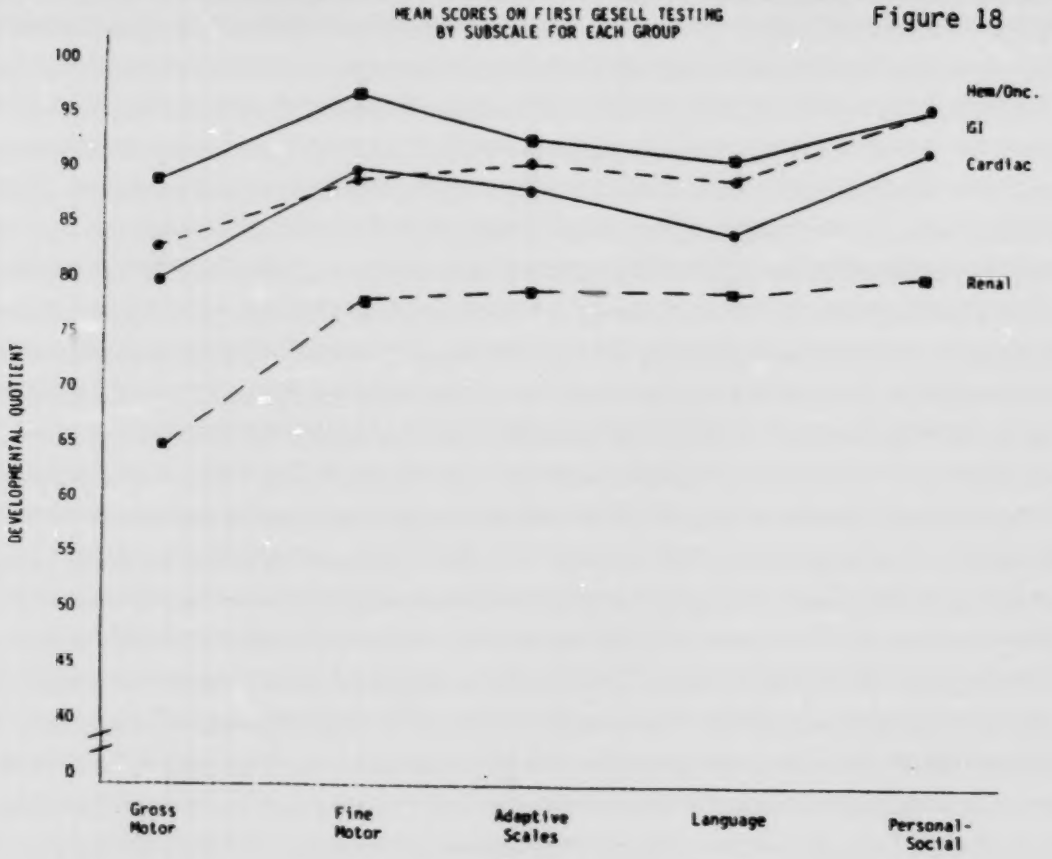
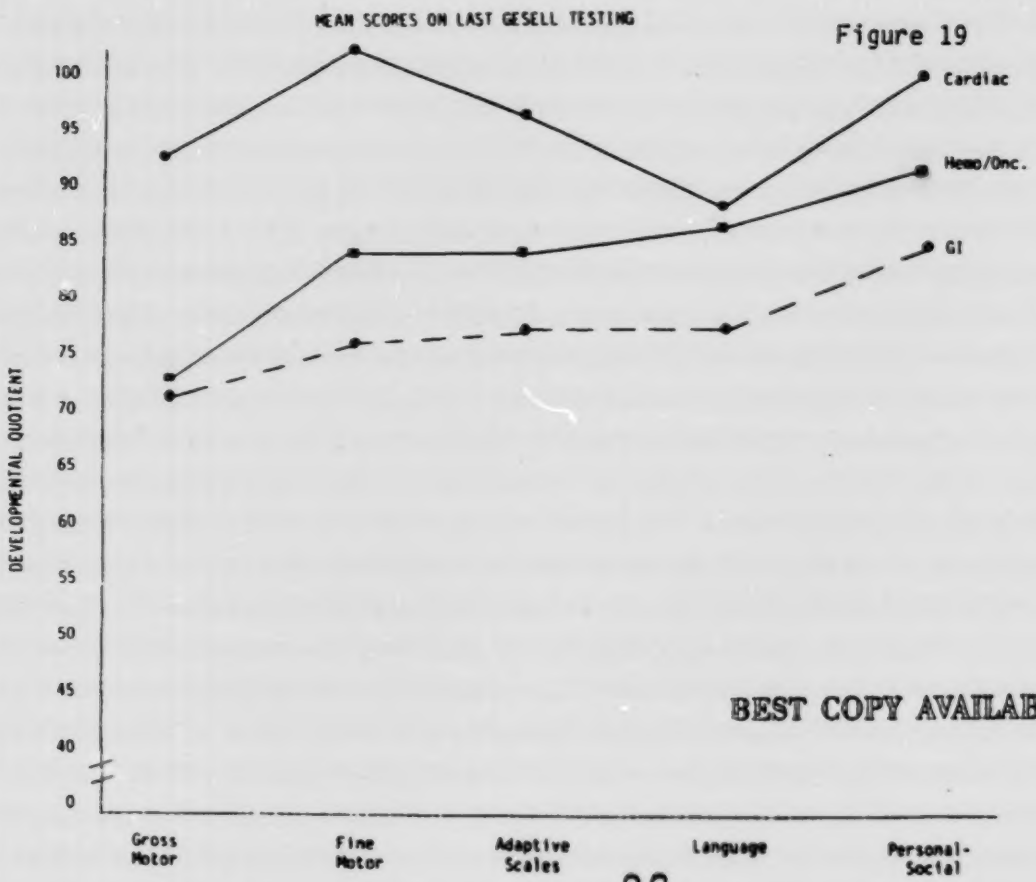



Figure 19

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Functional Status

The Functional Status measure (Stein, Heismann, & Jessop, 1982) indicated a range of functioning for the children in their ability to conduct daily routines. See Table V. The level of functioning in mood and everyday tasks remained basically the same throughout the project. This measure was not correlated with the initial Gesell score but was related to the last assesssment of cognitive status. The overall functional status was related also to other measures of the child's health status. Some of the single items of this measure describe common problems in this population. For example forty per cent of the children were dependent on medical equipment, 33% had eating problems, 23% had sleeping problems, and 48% were described as often being in a difficult/bad mood.

Table V

FUNCTIONAL STATUS

| | First Testing | | | | Last Testing | | | |
|---|---|---|---|---|---|---|---|---|
| | N | Mean | S.D. | Range | N | Mean | S.D. | Range |
| Cardiac | 12 | 82 | 12 | 54-93 | 9 | 79 | 11 | 61-93 |
| Gastroenterology | 9 | 79 | 16 | 46-100 | 4 | 70 | 16 | 57-89 |
| Hematology/Oncology | 7 | 73 | 20 | 39-96 | 5 | 87 | 15 | 61-10 |
| Renal | 4 | 74 | 10 | 64-86 | 3 | 77 | 24 | 50-96 |
| Overall | 32 | 78 | 15 | 39-100 | 21 | 79 | 15 | 50-10 |

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Behavior Record

After each developmental testing the examiner completed the Bayley Infant Behavior Record (1969) describing the child's behavior during the testing situation. A score was determined on the basis of 15 items (e.g. cooperation, persistence, endurance, emotional tone). The number of behaviors that were maladaptive or infrequently observed in normal children was calculated (Wolf & Lozoff, 1985). Table VI presents the data for the total group and by illness category. This group of chronically ill children showed a higher rate of suspect ratings than found for healthy groups (approximately 26% versus 14% respectively).

Table VI

BEHAVIOR RECORD

| | N | % Normal Ratings | Range |
|---|---|---|---|
| Cardiac | 13 | 75 | 27-100 |
| Gastroenterology | 10 | 69 | 7-100 |
| Hematology/Oncology | 8 | 76 | 40-100 |
| Renal | 4 | 77 | 69-87 |
| Overall | 35 | 74 | 7-100 |



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Parenting Stress

The Parenting Stress Index (Abidin, 1983) was administered in order to assess parent-child systems at risk for dysfunctional parenting. This measure was given approximately 2 months after the child's discharge from the hospital. Some parents indicated a low level of stress in their parenting, whereas others were highly stressed. Table VII present the mean scores by illness category and for the total group. The measure also yields subscores within the child domain and within the parent domain. Figures 20 and 21 indicate the scores obtained by illness groups, compared to the normative healthy groups of the standardization sample.

Table VII

PARENTING STRESS

| | First Testing | | | |
|---|---|---|---|---|
| | N | Mean | S.D. | Range |
| Cardiac | 11 | 251 | 37 | 188-307 |
| Gastroenterology | 10 | 243 | 25 | 201-277 |
| Hematology/Oncology | 9 | 259 | 41 | 184-313 |
| Renal | 2 | 270 | 57 | 230-311 |
| Overall | 32 | 252 | 35 | 184-313 |

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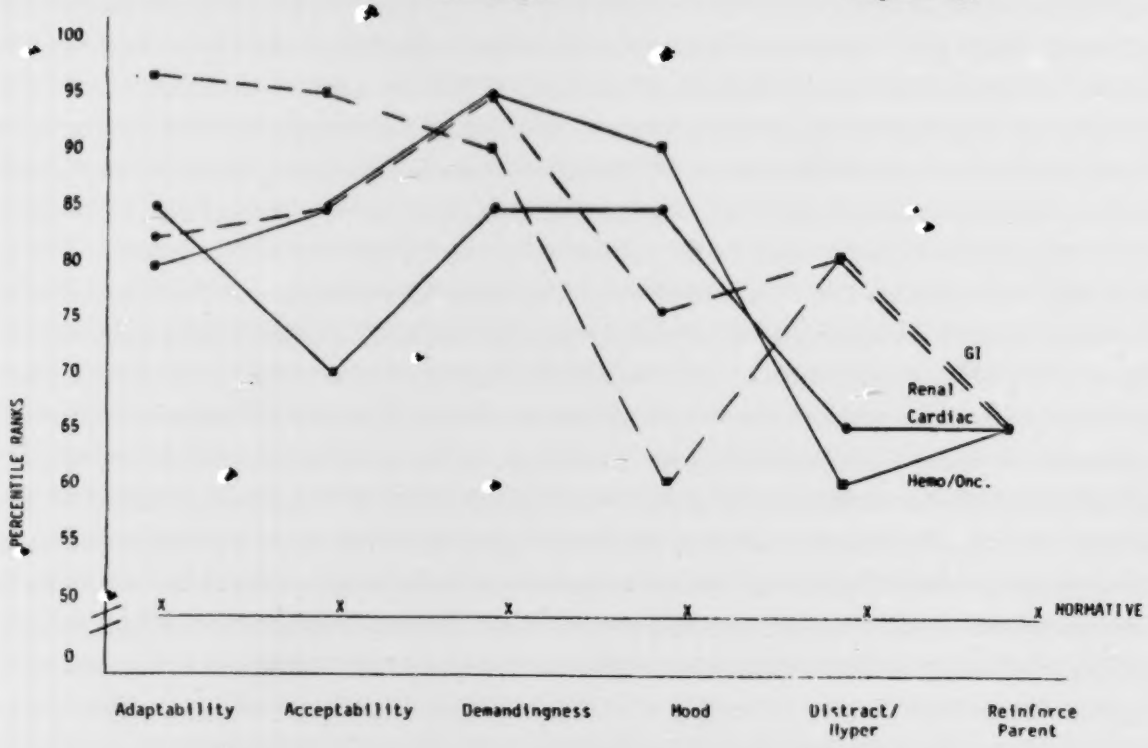
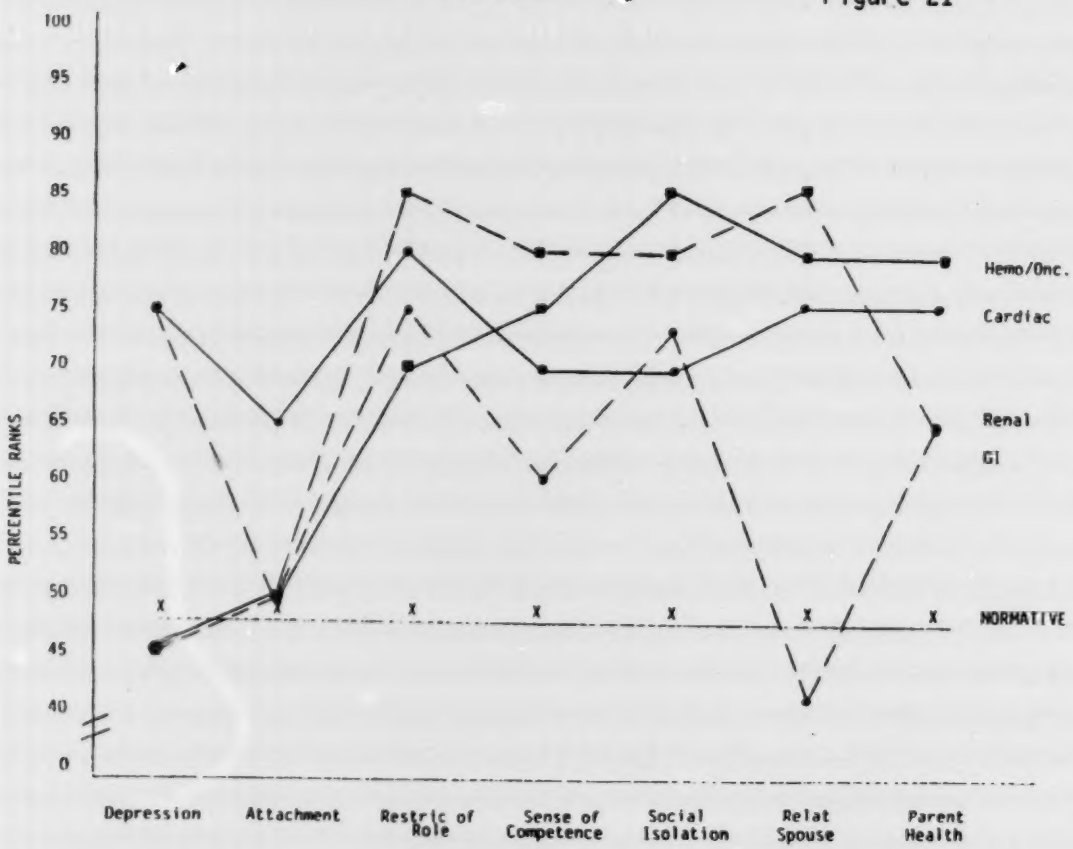
CHILD DOMAIN

Figure 20




PARENT DOMAIN

Figure 21



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It can be seen that some areas are particularly difficult for parents of chronically ill children and other areas do not create especially stressful problems. In the child domain high stress is felt in adaptability, acceptability, and demandingness, however the parents as a group do not experience stress in their interactions with their child. In the parent domain restrictiveness of role and social competence tend to be stressful areas.

The older the child, the more stress the parents experienced, in contrast to the normative group in which parents of younger children experienced a higher level of stress. The reverse finding in this group probably reflects the duration of time the parents have had to cope with the child's health problems. The score was not related to any single measure of the child's health status per se and indicated that the stress was not a function of how sick the child was. The index was related to the child's cognitive status, the behavior record score, and to the scores of mother-child responsivity measured during naturalistic observations.

A life stress score was also obtained as part of the Parenting Stress measure. Table VIII presents data by illness category and for the total group. The stress level is high as compared to a normative group (11% versus 50% respectively). The life stress measure related to the parenting stress index such that those families who experienced a number of life stressors were more at risk for dysfunctional parenting.

Table VIII

LIFE STRESS

| | First Testing | | | |
|---|---|---|---|---|
| | N | Mean | S.D. | Range |
| Cardiac | 11 | 9 | 8 | 0-23 |
| Gastroenterology | 10 | 9 | 8 | 0-29 |
| Hematology/Oncology | 9 | 15 | 15 | 0-41 |
| Renal | 2 | 14 | 1 | 13-15 |
| Overall | 32 | 11 | 10 | 0-41 |

Home Visit measures: Naturalistic observations were made of parent-child interaction during home visits. For those children who lived out of the area, observations were made during their hospital stay. Observations were made between one and 6 times during project participation. Table IX presents the mean scores for the first and last visits for four summary variables. The Home total score was dervived from three subscales of the Caldwell Home Inventory that have been shown to be particulary valuable in other studies. These three subscales are maternal verbal and emotional responsiveness, avoidance of restriction, and maternal involvement. A project derived rating scale based on items from a scale by Clarke-Stewart (1973) was used to rate maternal responsivity, child responsivity, and dyadic involvement. The scores



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indicate that a relatively high rate of responsiveness was shown and maintained, in spite of the sickness of the child. The home measures were related to the child's last measure of cognitive competence such that those children whose home total scores were higher scored higher on the cognitive measures. The home scores were also related to the parenting stress measure. Those parents who indicated a higher stress level in their parenting were observed to have lower home visit scores indicating less responsivity and a lower dyadic involvement. The home total scores were lower for those children who were sicker at the beginning, but, in general, the home visit scores were unrelated to the health status of the child. Parents were able to be highly involved and maintain a responsive relationship regardless of how ill their children were. The home visit scores were not related to the child's dependence on medical equipment, nor to any of the demographic measures such as social class of the family, maternal education, intactness of the family, sex of the child, birth order, nor country of origin of the parents.

Table IX

HOME VISIT

| | First Mean | Last Mean |
|---|---|---|
| Cardiac | | |
| Home total | 20 | 19 |
| Mother responsivity % | 88 | 81 |
| Child responsitivity % | 70 | 70 |
| Dyadic involvement | 3.6 | 4.1 |
| Gastroenterology | | |
| Home total | 14 | 13 |
| Mother responsivity % | 73 | 79 |
| Child responsitivity % | 66 | 70 |
| Dyadic involvement | 3.5 | 4.0 |
| Hematology/Oncology | | |
| Home total | 17 | 19 |
| Mother responsivity % | 69 | 81 |
| Child responsitivity % | 58 | 74 |
| Dyadic involvement | 3.4 | 4.4 |
| Renal | | |
| Home total | 17 | 18 |
| Mother responsivity % | 83 | 82 |
| Child responsitivity % | 80 | 70 |
| Dyadic involvement | 4.2 | 3.8 |
| Overall | | |
| Home total | 18 | 18 |
| Mother responsivity % | 79 | 80 |
| Child responsitivity % | 69 | 71 |
| Dyadic involvement | 36 | 36 |



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Stress Groups and Parent-Child Functioning: In order to examine the effect of perceived parental stress on parent child functioning, lower and higher stress groups were formed on the basis of the Parenting Stress Index. Those parents who scored above the risk point for the normative sample consituted the higher risk group and those who scored below the risk point consituted the lower risk group. The two stress groups were compared as to descriptive factors (Table X) and in terms of the scores obtained on the battery of measures. See Table XI. The two groups differed on a number of measures. Those parents who were experiencing less stress in the parent child relationship had children who scored higher on the developmental measures and scored higher on the home visit measures.

Table X

DESCRIPTION OF STRESS GROUPS

| | Lower Stress N = 18 Mean | Higher Stress N = 14 Mean |
|---|---|---|
| Age of child - months | 26 | 39 |
| % Boys | 50 | 57 |
| % Firstborn | 56 | 43 |
| % Intact families | 61 | 50 |
| Type of illness | | |
| % Cardiac | 33 | 36 |
| % Gastroenterology | 39 | 21 |
| % Hematology/Oncology | 22 | 36 |
| % Renal | 6 | 7 |

Table XI

PARENT-CHILD FUNCTIONING AS LAST MEASURED BY STRESS GROUP

| | Lower Stress N = 14[a] Mean | S.D. | | Higher Stress N = 10[b] Mean | S.D. |
|---|---|---|---|---|---|
| Developmental | 97 | 18 | * | 75 | 25 |
| Functional status | 78 | 15 | | 79 | 16 |
| Behavioral record | 13 | 2 | | 11 | 3 |
| Home-total | 19 | 4 | ** | 14 | 6 |
| % Mother responsivity | 87 | 10 | * | 70 | 20 |
| % Child responsivity | 78 | 15 | | 58 | 21 |
| Dyadic involvement | 4.7 | .6 | ** | 3.2 | 1.6 |
| Life stress | 8 | 8 | * | 15 | 12 |

* $p < .05$
** $p < .01$
[a] N varies 12-14
[b] N varies 7-10



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Family Problems

The families in the project experienced a number of life problems, other than the chronic illness of their child. Table XII presents the percentage of project families with specific problems. It can be seen that financial, marital difficulties, and emotional instability of a family member were very common problems for these families. In order to illustrate the multiproblem nature of these families, Table XIII presents the percentage of families by the number of problems. It can be seen that more than 50% of the families had 3 or more serious life problems in addition to the child's chronic illness.

Table XII

FAMILY PROBLEMS

| | % with problem |
|---|---|
| Financial | 56 |
| Legal | 20 |
| Housing | 22 |
| Lack of social support | 27 |
| Emotional instability | 44 |
| Marital difficulties | 50 |
| Drug/alcohol abuse | 25 |

Table XIII

Families with Serious Family Problems*

| | % |
|---|---|
| No serious problem | 24 |
| 1 problem | 22 |
| 2 problems | 11 |
| 3 problems | 17 |
| 4 problems | 9 |
| 5 problems | 6 |
| 6 problems | 13 |
| 7 problems | 2 |

* As described in Table XII

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Family Functioning

The group was divided into good or less good family functioning by the project staff at the completion of the project. These categories were determined, not on the basis of the number of family problems, but on the project staff's judgement of how well the family coped in spite of problems. A three point rating was used: good, questionable, and poor. The latter two categories constituted the less good group. Depending on the particular measure, the number of cases varied between 17 and 24 for the good group and between 11 and 19 for the less good group. More than half of the families were judged to be coping adequately by the time the project ended. Table XIV indicated that children and families scored higher on many of the project measures if the families were judged to be functioning better. The developmental scores and the child's functional status were unrelated to how well the family was coping.

Table XIV

FAMILY FUNCTIONING

| | Less Good N = 11 - 19 Mean | | Good N = 17 - 24 Mean |
|---|---|---|---|
| Developmental | 88 | | 88 |
| Behavior record % normal | 69 | | 78 |
| Beginning status | 36 | ** | 53 |
| Functional status | 78 | | 80 |
| Parenting stress | 261 | * | 237 |
| Life stress | 16 | * | 7 |
| Home total | 15 | *** | 20 |
| % Mother responsivity | 71 | ** | 86 |
| % Child responsivity | 64 | * | 76 |
| Dyadic involvement | 3.6 | ** | 4.5 |

* $p < .05$
** $p < .01$
*** $p < .001$

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Intervention Goals:

Sets of intervention goals were determined by the project staff to be accomplished during the child's hospitalization. Some of these goals were directed at the child and the child's hospital environment whereas others were directed at the parents. After the child's discharge from the hospital, goals were determined for the family/child system, for the child's long term adjustment, and for the family. At the completion of the project, three staff members evaluated each case and by consensual agreement determined if each goal was achieved or not for a particular case. See Appendix for the form "Intervention Goals Accomplished." Table XV presents a summary of the project's success in achieving the intervention goals. It can be seen that there was a higher rate of success during the child's hospitalization than after hospital discharge. Nonetheless, the overall rate of achieving the intervention goals was high. The lowest percentage of success was in achieving goals with the family per se and this result is not surprising as the family integrity/stability/functioning was expected to be the most resistant to change and highly related to non-project factors.

Table XV

PERCENT OF INTERVENTION GOALS ACCOMPLISHED

| | % Accomplished |
|---|---|
| During hospitalization | |
| For the child | 98 |
| For the family | 91 |
| Post hospitalization | |
| For the child | 86 |
| For the family | 79 |
| For the child/family system | 88 |

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The post-hospital intervention scores were correlated to measures of the child and family functioning. The number of intervention goals accomplished for the child and the family-child was related to measures at the home visit of maternal and child responsivity. Thus families for whom intervention was more successful were also rated as showing a more responsive home environment. Furthermore, for those families for whom a higher percentage of intervention goals were accomplished in the area of family/child goals after hospital discharge, the children scored higher on the Gesell developmental schedules at final testing and on the number of normal behaviors on the behavioral record at last testing. Intervention was more successful for those parents who originally experienced less stress in the parent child relationship and less life stress. Intervention success for the child and the family child system was unrelated to social class, maternal education, family status, sex of the child, birth order, age of the child, primarly language of the family, and proximity to the hospital. Thus we were successful across a broad range of factors in achieving a high percentage of the intervention goals. The health status of the child was not related to success in accomplishing family/child goals but the health status of the child was related to success in achieving child goals. A lower percentage of the child goals were achieved with the sicker child. The goals for the family itself were related to the social class and intactness of the family, as would be expected.

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## V. DISSEMINATION ACTIVITIES:

Major presentations have been made at National and International Meetings. We have presented different aspects of our program focusing on rationale intervention services and replication. We have spoken to a variety of audiences including pediatricians, psychiatrists, social workers, child life specialists, and parents of chronically ill children. The audience response to our program has been encouraging since there is still a relative absence of programs which deal with the emotional and cognitive needs of this emerging population of children. A list of our major presentations follows:

### PRESENTATIONS

Needs of Parents of Chronically Ill Children, M. Fauvre: Infant Development Association Conference, Children's Hospital of Los Angeles. November, 1985.

Issues of Hospitalization: Realities and Models of Intervention. N. Brill, and N. Klein. Infant Development Conference. Los Angeles, CA. November 2, 1985.

CHAMP: Children in Hospital, A Model Program: A Unique Intervention Program for Chronically Ill Children. N. Brill, S. Cohen, M. Fauvre, N. Klein, S. Clark and L. Garcia. 21st annual Conference for the Association for the Care of Children's Health. San Francisco, CA June 1986.

Problems of Development in Three Infants with Liver Transplants. N. Brill, N. Klein, L. Garcia, and H. Van Dam. World Association for Infant Psychiatry and Allied Disciplines. Stockholm, Sweden, August 1986.

A Model Demonstration Program for Chronically Ill Hospitalized Infants and Toddlers. N. Brill, S. Cohen, M. Fauvre. Infant Conference "87, Vulnerable Infants, Stressed Families: Challenge for Research and Practice. Los Angeles, CA February 1987.

Parental Stress and the Behavior of Young Chronically Ill Children. S.E. Cohen. In symposium "Child Health" B.J. Tinsley (Chair), at Biennial Meetings of the Society for Research in Child Development, Baltimore, April 1987.

Children's Adaptation to Illness and Hospitalization. N. Brill. John Adams' Day: Biological-Social Interaction and Children's Behavioral Development. UCLA, Los Angeles, CA, June 1987.

Chronically Ill Hospitalized Children. N. Brill. First Annual UCLA Conference or Preventive Psychiatry, Los Angeles, CA, October 1987.

A Plan for Planning: Developing Individualized Intervention Plans for Chronically Ill Children. N. Brill, S. Clark, M. Fauvre. Accepted for presentation to the 23rd Annual Conference for the Association for the Care of Children's Health, Cleveland, Ohio, June 1988.

A Parent Support Group: A Hospital-Based, In-Patient Model. M. Fauvre: Accepted for presentation at 23rd Annual Conference for the Association for the Care of Children's health. Cleveland, Ohio. June, 1988

At UCLA, presentations have been made to the nursing staff and the pediatric Interns and Residents on several occasions including Grand Rounds and noon conferences. Discussions of care on a case by case basis has been particularly fruitful. Our project was joined for some time by a Graduate Nurse learning psychosocial nursing care. She was able to bring a nursering perspective to our project and integrate some of our interventions into routine care at UCLA.

Presentations have also been made to the UCLA Hospital Auxiliary to the UCLA Board of Directors, the UCLA Cardiology parent Group and the UCLA hematology parent Group.

We have made several appearances before the San Fernando Child Guidance Clinic, and the Los Angeles Public School Board.

In addition, News media coverage by Cable News Network and CBS resulted in nationwide coverage of the our program over T.V. and radio.

NEWS ARTICLES/PROGRAMS

CHAMP Program. News Spot. Cable News Network. Nationwide Airing. September 1985.

Reducing Hospitalization Trauma for Children. N. Brill Science Editor Broadcast over CBS Radio Network. Week of January 22, 1986.

Pediatric Staff Champions of Children. Mediscene. September 1985, Vol. 8, Number 3.

We have a number of publications reaching a broad audience including our own staff and patient group at UCLA and a nationwide audience of health care providers.

PUBLICATIONS:

Brill, N., Cohen, S., Fauvre, M., Klein, N., Clark, S., and Garcia, L.: Caring for chronically Ill Children: An Innovative Approach for Care. Children's Health Care, Journal of the Association for the Care of Children's Health. Fall, 1987, Vol. 16, No. 2:105-113.

Brill, N.: Chronically Ill Hospitalized Children. Proceedings of the First Annual Conference on Preventive Psychiatry. Accepted for Publication.

Fauvre, M.: Including Young children with "New" Chronic Illnesses in an Early Childhood Education Setting. In press, Young Children, Journal of the National Association for the Education of Young Children. Winter, 1988.

Fauvre, M.: Preparing your Family for a Child's Hospitalization. In press, UCLA Health Insights, Winter, 1988.

Cohen, S., Brill, N., Fauvre, M., Klein, N., Clark, S., Garcia, L.: "A Guide for planning for the Psychosocial needs of the Young Hospitalized Child." UCLA, 1987. (In press).

Fauvre, M.: "When your child is in the Hospital." UCLA, 1987.

Clark, S.: "When parents need to be away while their child is the hospital." UCLA, 1987. (In press).

Cohen, S.: "Coping with Painful Medical Procedures." UCLA, 1987. (In press).

Brill, N.: "Development in the Young Hospitalized Child." UCLA, 1987. (In press).

VI CONTINUATION FUNDING

We have been funded for continuation by two funding sources

1) Los Angeles Unified School District has funded us for $70,000 a year to work with 14 children on the inpatient pediatric ward. This funding began 11 months ago and will be ongoing.

2) Regional Center has vendorized us for billing for Hospitalized Children for up to $150,000 per year. to work with 10 inpatients and a much larger group of outpatients.

Our proposal for outreach funding was apparently not accepted, although we have had no communication from the U.S. Department of Education.

## Appendix

Project devised/adapted measures

Presentations

Publications

1-3 __ __ __ Project # Name_____

4-5 Z 1 Form #

Intervention Goals Accomplished

During Hospitalization 0=not appropriate 1=no 2=yes

Child

6 __ child received regular child development/volunteer services

7 __ child communication with parents/staff facilitated

8 __ play therapy received

9 __ implemented plan to reduce child's anxiety

Parent

10 __ implemented plan to reduce parents' anxiety

11 __ parents visited child regularly

12 __ parents were able to work with staff to provide for child's needs

13 __ parents used counseling/parent sessions services

14 __ parents able to attend to own needs

15 __ parents able to attend to sibling's needs

Environment

16 __ room was personalized

17 __ age appropriate toys used

**Post Hospitalization - Family/Child**

18 __ family able to take care of child

19 __ family able to comply with medical regime

20 __ family encouraged age appropriate independence/ individuation

21 __ family encouraged opportunities for peer interaction

22 __ child's behavior acceptable to family

23 __ shared positive affect/enjoyment of child

24 __ sets appropriate limits/expectations

25 __ family able to maintain good parent-child relationship/attachment

26 __ family provided age appropriate activities

27 __ family followed through on recommended play therapy sessions for child

28 __ family followed through on referrals (e.g. nursery school/play groups, regional center, counseling)

**Post Hospitalization - Child** (Long term adjustment)

29 __ child appeared happy

30 __ child used language appropriate for developmental level

31 __ child played with toys, appropriate for developmental level

child improved in following areas

32 __ feeding

33 __ sleeping

34 __ irritability (whining, crying)

35 __ independence

36 __ sociability

37 __ cooperation

Post Hospitalization - Family

38 __ family able to attend to own needs

39 __ Parent able to return to work

40 __ maintain relationship with spouse

41 __ activities

42 __ family able to attend to sibling's needs

43 __ family follows through on recommended play therapy session for sibling

**Family functioning** 1:poor 2:questionable 3:good

44 ___ family functioning - overall

45 ___ financial - stable income

46 ___ legal -

47 ___ housing - stable, clean, hygiene

48 ___ social support used (extended family & friends)

49 ___ emotional stability of parents

50 ___ marital relationship

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Performance Status Scale for Chronically Ill Children

Adapted Karnofsky* Scale

| Percentage | Comments |
|---|---|
| 100 | Normal, no complaints, no evidence of disease |
| 90 | On medications but able to carry on normal activity with minor signs or symptoms of dissease. Good prognosis (i.e. cardiac, leukemia s/p induction, s/p bone marrow transplant). Disease does not hamper play. |
| 80 | Normal activity with effort. Some signs or symptoms of disease. On medications, but attends full school day or plays normally with some physical problems (i.e. slight cyanosis, tires easily). No special equipment. |
| 70 | Cares for self. Unable to carry on normal activity or do active work. Partial school day, decreased endurance, (i.e. weak cyanotic tires easily, irritable). Best functioning TPN/Dialysis patients. |
| 60 | Requires occasional assistance, but is able to care for most of his needs. Homebound. Frequent medical appointments. Medical equipment necessary. |
| 50 | Requires considerable assistance and frequent medical care. Out of hospital but in setting of a home hospital (TPN, dialysis, disabled cardiac). Weekly clinic visits. |
| 40 | Disabled, requires special care and assistance. Nursing round the clock with hospital set up at home or in hospital with moderate problems. |
| 30 | Severely disabled. Hospitalization indicated though death not imminent induction chemotherapy, dialysis, umcomplicated bone marrow transplant. |
| 20 | Hospitalization necessary. Very sick, active supportive treatment necessary (Intubation, blood necessary, complicated bone marrow transplant). May be in Ill. Death possible. |
| 10 | Moribund, fatal processes progressing rapidly, ICU, Death imminent. |
| 0 | Dead |

(Cancer 1948; 1:634-656)

Prognosis Scale

| Bad | Questionable | Good |
|---|---|---|
| Unlikely that child will survive<br>> 75% chance of death | Unpredictable outcome | Likely survival long term.<br>> 75% chance of life with minimum complication |
| Hematology/Oncology<br><br>Poor prognostic group at diagnosis | Hem/Onc<br><br>Need BMT | Hem/Onc<br><br>Good prognostic group at diagnosis<br>3 years off chemo s/p BMT |
| Cardiology<br><br>Very complex congenital disease (e.g. single ventricle hypoplastic left heart | Cardiac<br><br>Repairable cardiac disease prior to treatment | Cardiac<br><br>Tetralogy of Fallot with good chance of repair<br>VSD (simple) or s/p definitive repair |
| Short Bowel Syndrome<br><br>Complicated TPN, pseudo-obstruction/TPN | Short Bowel<br><br>TPN - no other problem | Short Bowel<br><br>Weaning off TPN |
| Renal<br><br>Renal failure plus other problems | Renal<br><br>Hope of transplant | Renal<br><br>s/p good transplant |
| Gastroenterology<br><br>Liver debilitated, no hope of transplant | GI<br><br>Hope of transplant | GI<br><br>s/p good transplant |

# Parental Stress and the Behavior of Young Chronically Ill Children

Sarale E. Cohen

The growing number of infants who survive due to recent advances in medical technology has led to an increased interest in the behavioral adjustment of young chronically-ill children and parental factors associated with childis psychosocial status. Studies have shown that children with chronic illness are at risk for adjustment problems. The factors associated with psychological status need to be explored.

Parenting stress and parent-child behavior were studied as part of a longitudinal study of 28 chronically-ill infants and young children. Interviews and standardized instruments provided measures of areas stressful for the parents with particular emphasis on the parent-child system. Ratings of parent-child interaction were obtained during repeated home visits. In addition, the childis developmental level and ability to carry out age appropriate social role were also measured.

The results suggest that as a group, the parents of chronically ill children experienced a high level of stress in life events and in parenting their children. In spite of the anxiety connected with the illness some parents were able to maintain a well functioning parent-child system. The major areas of stress expressed by the parents were in terms of their own characteristics such as feeling socially isolated, being restricted in their roles, and having problems with their own health. As a group they did not experience high stress, in depression, attachment to their child, or their own feelings of competence. In areas dealing with the childis characteristics,

greatest stress was experienced in seeing the child as unadaptable, demanding, and negative in affective tone. Nonetheless, the parents had good feelings from the parent-child interactions and were reinforced by the child's qualities. The child's daily dependence on special medical equipment (as dialysis, total parental nutrition, oxygen) was not associated with parental stress scores. Neither the degree of sickness nor the amount of medical attention required affected the acceptability of the child to the parent. The older the child, the greater overall stress the parent reported.

Regardless of stress level parents were able to engage in positive social interactions with their children. Yet children of highly stressed parents were less responsive to the parents and were less able to carry out age-appropriate daily social tasks. Although the emotional adjustment of the children was related to parental stress, cognitive development of the children was more highly associated with degree and duration of their sickness.

Case history material will be presented to illustrate risk factors associated with poor psychological functioning and high parental stress. Some families were able to be highly involved with their children, comply with procedures and provided excellent care during the child's acute stages of illness during the child's hospitalization. Maintaining adequate functioning for the children and the parents outside the hospital setting was difficult for some families. Lack of medical follow-up leading to severe neglect was found in stressed families and in families whose children were unresponsive and gave little satisfaction to parents. Implications for supportive interventions for the child and family and for social policy will be discussed.

Presented as part of a symposium "Child Health" in the context of the Family and Public Policy, BJ. Tinsley, (Chair), at biennial meetings of Society for Research in Child Development, Baltimore, April 1987.

Article in press, Young Children Winter, 1988

# Including Young Children with "New" Chronic Illnesses in an Early Childhood Education Setting

Mary Fauvre, Ph.D.

The effects of modern medical science and technology are being felt in places far beyond the hospital setting, and the early childhood educator may soon have more experience with some of these medical successes. Children who are born with a number of different birth defects have been treated successfully with surgeries and modern drugs. Children who develop cancers of various types are undergoing strenuous but successful treatments of chemotherapy and radiation. Organ transplantation has become more available in the case of children whose livers or kidneys have not developed properly, and congenital heart defects can often be corrected by intricate surgeries now. These conditions which were previously thought to be terminal have recently been relegated to the list of "chronic", although the classification is usually still considered to be "life-threatening" chronic illness (Ruccione, 1983). These children often lead very normal lives, punctuated by trips to clinics or hospital perhaps, and they are often a part of regular school and community programs. Unfortunately, very few non-medical professionals have received the training to feel comfortable with this new population, and

they may not feel able to help in identifying the needs of these children and their families (Hobbs, Perrin & Iveys, 1985).

While this is a new group to plan for school or program inclusion, there have been a number of other situations where children have had specialized medical needs. For years children with chronic asthma conditions, sickle-cell anemia, and juvenile diabetes have been successfully included in regular school settings, and there is every reason to expect that these children with "new" chronic illnesses will also be included. PL 94 - 142 in fact recognizes "health impaired" as a category of children to whom services must be offered in the least restrictive environmrnt, so by law they must be included. A key factor to successful schooling of these children however, will be careful communication and collaboration between parents, school, and health care providers; there must be a high level of trust and understanding on the part of all. Parents are usually overwhelmed at the initial diagnosis of their child's condition, but by the time their child is ready for school (either nursery or elementary school) they have probably developed a certain level and style of coping with their child's health problem. A teacher, on the other hand, may feel quite frightened or disconcerted about the presence of a young child with a "weak heart", who may tire easily, become slightly blue, or need specific medication on a predetermined schedule. If the parents can explain the circumstances carefully

enough, and if the teacher can feel comfortable with the child then there is every reason to expect successful school entry. Teachers must remember that the child with a health condition is first a child like all other children, and only secondly should they address the health problems; then it should be possible for the child to be included as a normal member of the group. The following specific suggestions have come from working both with parents and teachers who have had children with chronic life-threatening illnesses in their classes. The presentation is not meant to be exhaustive, but rather to aid in raising further questions, and in raising the awareness of teachers and other non-medical professionals who work with these children.

The first concept is perhaps the most important: The needs and successes of these children with chronic life-threatening illnesses are similar to those of other children. Even though they may have been through extremely difficult medical procedures, and there may be restrictions on their regular activities, they are children above all. Parents often complain that it is difficult to discipline their young child when they know he is being treated for leukemia, because they fear that his condition may in fact be terminal rather than chronic. Teachers face a similar dilemma, and it is tempting to "give in" and be "softer" on such a child, but in reality it is a disservice to the youngster. Siblings become jealous of special favors or

privileges, and classmates too will resent the child if there is special attention. This is similar to any event which makes a child different from the others. The frequent snacks a diabetic child may require, or the extra attention given to an asthmatic child may be appropriate for the child°s medical condition, but the treatment must be considered carefully as it affects the class:s social and emotional environment as well.

The classroom experience and socialization opportunities are important for all children, and they are particularly important for children with chronic illness. In a classroom setting, a child has the opportunity to explore and try out new skills, and to achieve mastery or recognize limitations if appropriate. Parents of a child with health problems frequently are over protective and do not allow their child to attempt new activities independently (Lansky, Cairins and Zwartjies, 1983; McCollum, 1981). Once enrolled in a school program however the child will have numerous opportunities for exploration and discovery which might otherwise be unavailable. The child will benefit from being in a group setting, and will have an opportunity to develop a sense of independence and self sufficiency which is so important between the ages of 3 and 8 years. (Adams and Deveau, 1984; Deasy-Spinetta and Spinetta, 1980).

The converse to this idea of recognizing the normal child aspect first is the concern that since many of these children do

not look sick, the teacher will forget that they may be slightly more fragile, or require extra attention to energy levels or medication needs. Children who have had successful heart surgery for example, may look perfectly healthy, and may in fact be perfectly healthy, but they may be at risk of overtiring with overexertion and need restricted activity levels for a period of time after their surgery. Children on chemotherapy may look no different from other members of their class (Deasy-Spinetta and Spinetta, 1980) unless there has been temporary hair loss, but their immune systems are more vulnerable, and they catch colds, flus, and other common childhood illnesses more easily. The same is true for children who have received organ transplants, or who are taking certain medications. The healthy-looking child may require only slightly more vigilance at certain times, but that extra attention to potential trouble may protect against other more serious setbacks.

The key element to successful integration of these children in school settings is communication between parents, teachers, school nurse if available, and health care providers, but information sharing is a sensitive event (Chekryn, Deegan and Reid, 1987; Schulz, 1978). Parents may feel that once they have explained their child's condition, that the teachers now understand as much as they do. Or teachers may feel that the medical details are more specific than they need, and they may

feel uncomfortable hearing about things which have become routine for parents. Some families and clinics have found it helpful to start with a form similar to the one included here, which lists more details than the normal school record charts (Hansen and Jeppson, 1986). Other parents have written detailed descriptions of their child's condition, explaining exactly what occurs at monthly clinic visits. They have found that children make references to their experiences which the teachers cannot understand without the careful explanations. What does it mean when a child comes to school after a day's absence, and proudly shows his three or four bandaids and announces, "It took four sticks this time". The teacher might not recognize his reference to the IV chemotherapy, and may not know how to respond. Often the child will elaborate or explain more if the teacher pursues with questions, but just as often it seems that the child is not interested in further discussion, and the teacher is left feeling rather inadequate.

Conferences are another important way to communicate information about a child's condition or treatment. It is probably a good idea for the teacher to take notes at such conversations, and not to rely solely on memory for details. Since parents have become the expert on their child's health status, and since parents are so involved and concerned about their own child's welfare, they may make assumptions about a

teacher's understanding even as they are trying to communicate what they think is important. A teacher of a child with sickle-cell anemia should be told directly to pay careful attention to the child if there are complaints of a specific localized pain; it is something to be taken seriously. Or similarly, a teacher may not realize upon hearing that a child is "immuno-suppressed", from cancer treatments or organ transplant medications, that that child is highly susceptible to any contagious germs, and that exposure to some common childhood illnesses like chicken pox may be life threatening. Parents who ask to be informed if there is an exposure to chicken pox really mean that they want immediate information, since there is an antidote available if a child is treated within 72 hours after exposure. Such specifics are important and must be spelled out clearly to ensure that what the parents have told has been thoroughly understood. Occasionally, a teacher's misconception or own experience with an adult patient may need to be addressed or disspelled in order to facilitate complete understanding of the child's health.

There are times when teachers may want more information than parents can give, and it may be appropriate for school personnel to consult with the doctors or medical staff treating the child (Chekryn et al, 1987; National Cancer Institute, 1984). Of course, such discussions must be held only with the consent of the parents, and all information must be recognized as confidential.

After a child has been through a medical crisis, or has finished a series of treatments, some parents feel it is important not to share information or prejudice others who will be working with their child. This is often true for children who have been treated for any of the childhood cancers. A child may have had chemotherapy for two or three years, and the teachers may have been included and informed thoroughly, but once treatment is over, new teachers may not be told anything. This makes it difficult for teachers who may know a little about the child's history, but not be informed about current status. That is an issue for the parents and teachers to work through on their own. Parents are often in a quandry as to how much to discuss, and what information is important to which staff members. It may be an appropriate time for a school nurse or administrator to step in, and act as a screen for such information.

With good communication, parents and teachers can work together, building a sense of trust and respect which works to the child's best interests. If a special school event is planned for the future, a teacher might be very helpful in alerting the parents of a child who has low energy levels; perhaps they could limit other activities for a few days, and help the child to prepare for the school occasion. Similarly, if a child will be starting a new treatment or new medication which may have noticeable side effects, the teacher will welcome such warning and

information to help interpret the child's behavior in light of the medical circumstances. Teachers need also to have ready access to emergency information, and to know what to look for in terms of onset of crisis, whom to call and what to do should there be an unusual situation involving the chronically ill child. Is there any reason that the local hospital should be informed before treating a child's broken arm or suspected concussion? Such information is better learned ahead of time rather than in crisis circumstances.

A slightly different aspect of information sharing is the anticipation of questions raised by other children in the class. Teachers must first be comfortable with their own understanding of the medical details, and should have support from the parents before exploring the questions of the other children (Chekryn et al, 1987; American Cancer Society, 1980). Sometimes the medical center where the child is treated will have a nurse or psychologist who specializes in school visits and explains the medical aspects to the children. Issues commonly raised include causes of the illness, or changes in appearance, especially hair loss or other side effects of medication (National Cancer Institute, 1984). Children in classes with a chronically ill child often need reassurance that they will not catch the same germ; is having a heart condition contagious? Parents of the other children might also need such reassurance, and might have

questions of their own. The growing awareness of AIDS and AIDS Related Complex has sensitized many to the issue of communicable germs, but the chronic, life-threatening illnesses discussed here (cancer, heart disease, kidney disease, or liver disease) are not contagious. Depending on the circumstances, the teacher and parents of the chronically ill child can work together to present relevant information, with the help of the medical center if appropriate.

The concept of parents working with teachers when planning for a chronically ill child cannot be overemphasized. Parents have been through major events concerning their child's health, and they will be appreciative of a teacher's support. Parents' anxiety levels may be extremely high, and it is not unusual for an apparently minor problem to raise stress levels of greater dimensions than would seem appropriate. Teachers can be sensitive to the the parents' needs by making an effort to include positive topics in conversations, without letting the "problems" become the dominant or exclusive theme. Another potential pitfall is the quick response of guilty feelings parents report, in reaction to many situations. Teachers can reassure parents as to their time and involvement opportunities, without letting the parents feel inadequate or unsupportive if they are unable to spend more time with school activities. A final area of advice for teachers is to allow parents of chronically ill children a little extra time in

making decisions about their child's school planning (Hansen and Jeppson, 1986). The parents have so many variables to consider, and are often fearful about anticipating the future, that school decisions may take on heavier meaning than in other circumstances.

It is a tribute to modern medical technology that information such as that presented here is even necessary. As recently as ten or fifteen years ago, no one worried about the early schooling experiences of a child with leukemia, or a defective liver, or certain heart conditions, because such diagnoses were virtual death sentences. Now, the opportunities for normal school experiences and program opportunities are vast. Parents of these children look anxiously for schools they trust, where their children can be a part of the regular program, but where they will receive a certain gentle understanding. As one parent said, "After all he went through as a baby, he <u>deserves</u> a little extra attention, but I don't want him to be different from the others." Clearly that presents both a dilemma and a challenge for parents and educators to address together.

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MEDICAL MANAGEMENT INFORMATION FORM
(Physician's Directions)
(adapted from Hansen and Jeppson, 1986)

_____ _____
child's name birth date

_____ _____
address parent or guardian

_____ _____

Diagnosis: _____

Symptoms: _____

Prognosis: _____

MANAGEMENT INFORMATION FOR THE SCHOOL:

1. Will medication or treatment be administered at school? Yes/No

   If yes, by whom? _____

   At what times? _____

   Any special instructions or precautions? _____

   _____

2. What considerations affect this child's ability to participate in the classroom?

   Special place in classroom due to hearing, vision or mobility problems?

   _____

   Special physical assistance? _____

   Help with toileting? _____

   Help with eating? _____

3. What considerations affect this child's ability to participate in physical education or playground activities?

   Endurance? _____

   Activity restrictions? _____

   Need for special monitoring? _____

   Can the child judge his/her exertion level appropriately?
   _____

4. What aspects of the child's condition might require preparing the other children in the classroom?

   Special equipment? _____

   Physical appearance? _____

   Speech characteristics? _____

   Seizures? _____

   Behavioral characteristics? _____

   Increased suscestibility to
   illness or disease? _____

5. What side effects of medications might affect the child's behavior?

   _____

   _____

   _____

6. When would you like the teacher to contact you? _____

   _____

   Under what special circumstances? _____

   _____

At what intervals? _____

In an emergency situation, must you be notified before treatment?

_____

What is the best time to reach you? _____

Other comments: _____

_____

_____

_____ _____

name of physician address

_____ _____

phone

WHEN PARENTS NEED TO BE AWAY WHILE THEIR CHILD IS IN THE HOSPITAL

When it is necessary for you to be away while your child is in the hospital some of these suggestions can help to ease this separation:

- Always tell your child when you are leaving. Always Say good-bye even though it's difficult.

Leave a picture of yourself with the child.

Leave a personal belonging of yours such as a sweater or article from your purse or pocket that your child can keep and hold.

Arrange to call at set times or to have your child call you so that he or she can look forward to a phone conversation with you.

If you know when you'll be able to return tell the hospital staff so they can help your child to remember when you are coming back.

Child Development Services staff may be able to arrange for volunteers from the playroom to spend extra time with your child during your absence.

Child Development Services staff may be able to help you to make a tape recording to leave with your child so he or she can listen to your voice. They may also be able to help you to make a tape recording to leave with your child so he or she can listen to your voice. They may also be able to help you to make a recording with your child to take with you to play for family members at home.

Please talk with us about any other ways that you think we can be of help to you and your family when you need to be away while your child is in the hospital.

# Additional Resources

**The following books may be of help to parents who are preparing their families for a child's hospitalization:**

- ***Curious George Goes to the Hospital***

- ***A Hospital Story***
(This book contains explanations in fine print whch accompany the pictures and which parents can read to anticipate the child's questions.)

- ***Why Am I Going to the Hospital?***

All of the above books are good for preschool age and up; *A Hospital Story* is directed to the school-age child.

Article in press, Health Insights, UCLA, Winter, 1988.

# Preparing Your Family for a Child's Hospitalization

*By Mary Fauvre, Ph.D.*

Mrs. Jones was very worried about her daughter's upcoming heart surgery. In fact, she was so apprehensive that she had told four-year-old Sarah that Mommy had to go to the hospital for an operation and that Sarah could go with her to stay overnight. She could not bring herself to tell Sarah about any of the things she would see, or feel, or any of the reasons for the approaching events.

At the last check-up before Sarah's admission, the pediatrician asked Sarah if she had any questions. Mrs. Jones blurted out the story she had concocted as her cover-up. The doctor feared that Sarah would be so shocked when the truth surfaced and her trust in her mother so shattered that he tried to persuade Mrs. Jones to tell Sarah of her impending surgery.

Mrs. Jones' fears about Sarah's surgery are very common. Most people who enter the hospital have a general feeling of anxiety. If the reason for hospitalization is serious, the person may also fear the outcome and the effect on future health. When the patient is an adult, presumably some questions can be answered and trust in the care and attention expected from the hospital staff established early. However, when the patient is a child, the questions are less apparent and the child's trust is still tied very closely to the parents. If the parents are themselves mistrustful, or find it hard to be truthful, the child's sense of trust will be threatened.

**Forewarned is Forearmed**

Perhaps the best strategy for families when a child is faced with hospitalization is to become as informed and educated as possible. If the family understands the procedures to be done, the child will feel more comfortable. It is helpful for the parents to understand children's fears. These generally center on fear of loss, especially of the parents, or of love; fear of hurt, pain and body mutilation; and apprehension of strangers doing for them what their parents usually do.

An informed family can anticipate the sequence of events. If parents tell their children that certain events will take place and those events do then occur, children will continue to trust their parents, even if the events result in some pain. In Sarah's case, the pediatrician arranged for her whole family to visit the hospital before the surgery. He contacted the pediatric ward and asked for a Child Life Specialist (also referred to as Recreational Therapist or Child Development Specialist) in charge of pre-hospitalization visits. This person advised that Sarah and her brothers be treated with openness and honesty and that they be encouraged to ask questions and learn all they could.

**The Hospital Tour**

Part of being informed includes visiting the hospital before the child's scheduled admission, if possible. There are times, of course, when distance or timing of an illness make tours difficult or impossible. If the hospitalization is planned, a tour can prove helpful for the entire family. Parents are often anxious about events for their children. That anxiety is communicated to their children. If the opportunity is available to tour the ward, to find out where Mom and Dad will be, to learn where the food comes from, to see where Mom and Dad will sleep if rooming-in is available, and to locate the playroom or play yard, many questions can be answered before they become anxieties.

Visits prior to admission can also be helpful to siblings, who tend to feel jealous of all the attention the hospitalized child receives. Often the hospital can give the visitors some simple medical supplies for dramatic play at home, such as bandaids, alcohol wipes, dummy syringes, etc., so that they can administer medical care to their dolls or teddy bears.

**Age of Child Important**

As parents become informed regarding the surgery or hospitalization, they should keep in mind their child's age and needs. For instance, an infant will not benefit as much from a pre-hospitalization tour as will a pre-schooler. However, the tour may still be useful for the infant's brothers and sisters. A school-age child may be able to ask questions and articulate worries, whereas a younger child may not be able to say what is bothersome.

A visit the day before admission is probably appropriate for a young child, but an older child can handle the information several days to a week beforehand. When a child asks a question, it is best to try



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to answer just what is asked and not to elaborate unless pressed further. A good strategy is to ask the child the same question: "Well, what do you think will happen when . . ." This will help the adults find out how much the child knows, or what misconceptions exist. It is very important for the adults dealing with the child not to put words into his or her mouth.

Parents and health care personnel should use a vocabulary geared to the child's level. All adults should let the child lead the discussion. Also, remember that the child is not asking for extensive medical details. The answer to "Will it hurt?" regarding a tonsillectomy should include something about anesthesia allowing them not to feel the surgery. However, children should be told about having a sore throat afterwards and reminded that they will get to eat ice cream or their favorite soothing foods.

Medical personnel, pediatricians and nurses can be helpful with advice about explanations for a child. In addition, many hospitals have Child Life Specialists who can help prepare a child beforehand, answer questions in a way the child will understand and often model behavior for the child, thus giving permisson for the child to voice his or her reactions to the situation.

Using puppets and dolls, these specialists encourage role playing with the child to explore underlying fears. Planning and scheduling such sessions depends on several variables: length of time available before hospitalization; level of the child's and/or parents' anxiety; and the child's age and abilty to understand the preparation. The parents' job is to be the main source of reassurance to the child. They must be able to interpret the hospital and its events to their child. If they are well informed and prepared themselves, they can help tremendously in the job of healing the child. Should an illness become more serious and change to life-threatening or terminal, the focus at the psychosocial support care would change from what is described here. Often the supportive services will center more closely on the family, and include family sessions to help in dealing with the extensive emotional turmoil. Still, however, the child's needs and understanding will be of foremost importance in gearing discussions to an appropriate level.

In the case of Sarah and her mother, the doctor's advice was followed. They visited the hospital before Sarah's scheduled admission. Mrs. Jones told Sarah that the doctors needed to fix a little hole in her heart which did not belong there. She told Sarah that the doctors did not know why the hole was there, but that they knew how to sew up the hole so it would not cause any trouble. Mrs. Jones said that Sarah would be in the hospital for several days, but that Mommy would stay with her. Mrs. Jones felt comfortable with the hospital staff they met, so she was able to relax as she told Sarah about upcoming events.

Sarah's younger brother felt so pleased to be included in the "action" that he was proud to be able to help his big sister. He was also thrilled with the prospect of staying with his grandparents all by himself. Sarah only wanted to know if she could bring her teddy bear and if he would get a hospital bracelet too. The child life specialist assured her that the bear could come and that he would receive a bracelet too and that they would even put a bandaid on him, if she thought he would need it. The child life specialist fixed two medical kits for Sarah and her brother to take home and recommended a few children's books. Sarah did not fully understand the meaning of her upcoming surgery, of course, but she know at least that her mother was supportive and trusted her.

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Pamphlet in press UCLA 1988

WHEN PARENTS NEED TO BE AWAY WHILE THEIR CHILD IS IN THE HOSPITAL

When it is necessary for you to be away while your child is in the hospital some of these suggestions can help to ease this separation:

Always tell your child when you are leaving.. Always Say good-bye even though it's difficult.

Leave a picture of yourself with the child.

Leave a personal belonging of yours such as a sweater or article from your purse or pocket that your child can keep and hold.

Arrange to call at set times or to have your child call you so that he or she can look forward to a phone conversation with you.

If you know when you'll be able to return tell the hospital staff so they can help your child to remember when you are coming back.

Child Development Services staff may be able to arrange for volunteers from the playroom to spend extra time with your child during your absence.

Child Development Services staff may be able to help you to make a tape recording to leave with your child so he or she can listen to your voice. They may also be able to help you to make a tape recording to leave with your child so he or she can listen to your voice. They may also be able to help you to make a recording with your child to take with you to play for family members at home.

Please talk with us about any other ways that you think we can be of help to you and your family when you need to be away while your child is in the hospital.

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Sue Clark, M.A.

Pamphlet in press UCLA 1987

# Coping with Painful Medical Procedures

Sarale E. Cohen, Ph.D.

It is difficult for parents to bring their children to the clinic or hospital and stand by as the child undergoes painful and stressful medical procedures. Modern medicine has increased the scope of procedures and many of these may be unfamiliar to the parents as well as to the children. It is not possible to avoid these procedures, but there are some things that can be done to make the situation easier for children and their parents. This booklet offers a few suggestions that may help children and parents cope.

1. An important goal for parents is to try to keep themselves calm, informed, and receptive to their child's needs. When parents are agitated and attempt to hide their own worry, their child will quickly sense that anxiety and perhaps become even more upset. Of course, the child's worries will increase the parents' anxiety, but it is helpful to try to stay relaxed.

Parents themselves should be informed about their child's treatment. Staff, nurses, doctors, and information in booklets are all available to increase parental knowledge and to answer their questions. These resources should be used if possible.

2. Parents should give their child the information that is important for him/her to know.

A good way to begin is to find out what the child knows and what the child thinks will happen. Asking questions of the child to find

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out his/her ideas, or asking the child to draw a picture may be an appropriate starting point.

Providing children with appropriate information has been shown to help decrease children's anxiety. However for the information to be appropriate, it needs to fit the child's level of understanding. Parents generally remember the child's developmental level in their daily explanations but under stress this may be overlooked. Explanations should be short, with specific examples, if possible. The discussion should not be more than the child can understand or not more than the child wants to hear. Explanations can generally be given in a positive tone keeping in mind that it is a way to establish truthfulness and trust. One hospital group has suggested that you can use an explanation similar to the following: "The doctor has to find out how healthy and strong you are. When the doctor looks at your ears and nose and mouth and chest and legs, s/he can see the outside of you. The doctor needs to look at your blood and urine too--so that s/he can see the inside of your body. It will hurt, but it won't keep on hurting. It stops hurting by the time (give example that child can understand) it takes for a TV commercial."

In talking to children, try to use neutral, non-emotional words. For older children "opening" or "incision" is preferable to "cut," or "oozing" instead of bleeding. Neutral words tend to be less scary and permit the child to think in less harmful ways.

Parents might need to check again with their child as to what s/he understands after the explanation. The child may need more information to correct misconceptions.

It is important for parents to listen to what their child says. What does the child say to his/her parents or other people before, during, and after a procedure? If parents listen carefully, they can try to build upon their child's thoughts and ideas.

Discussion with the child about procedures should be in a simple language, avoiding ambiguous words. The focus should be on concrete aspects - what the child will see and hear and what the child has to do. Physiological explanations are not helpful to young children. They do not need to know what will happen from a medical point of view, only from what their experience will be like. They do not need information about parts of the procedures that they will not experience directly.

The question of just when to tell a child prior to a major procedure is frequently asked. Generally it is thought that for children less than 4 years old, it is sufficient to tell the child no sooner than the day before. Very young children lack the ability to prepare ahead of time and therefore may be overwhelmed if they have too much time to think about the procedure. For children between 4 and 7 years, several days is adequate for major procedures. Children in the 4 to 7 year range can think about the procedure ahead of time and can plan their questions and coping. The "Child Life" program on the ward can aid in this preparation. A preparation appointment can be scheduled

with them (825-5602) ahead of time. They can help a child and the parents to be informed, to talk about and play through ideas and feelings. Parents should be aware of what their child has been told in the preparation and build upon that information.

Truthfulness is very important. If a procedure is going to be difficult, it is not helpful to say that it will not hurt or even that it will be over in a minute. It is better to acknowledge that the child will experience some discomfort --- "some children say it feels like a pinch," "some say it stings," "some children find it helpful to take deep breaths" or "some children cry and it's o.k. to cry or say ouch". Then provide the child with something he or she can do during the procedure. Parents can suggest concrete things for the child to do such as holding mother's hand, turning her/his head away, counting, singing a song, pretending they are someplace where they are having fun, or watching the second hand on the clock.

3. Parents who are comfortable with staying may want to arrange to stay with their child during the entire procedure, if possible.

The child may protest more if parents are at the child's side--but this protest may be what the child needs to do.

Parents may have comforting objects nearby such as the special blanket, stuffed animals, or favorite toys, to soothe and calm the child.

4. Rehearsing what is going to happen is another useful strategy.

For example, if the child is going to have a cardiac catheterization, s/he will need to be very still for a long period of time. Parent and child can practice being very still (like an animal hiding in the forest). Parents can help their child choose just what s/he would like to think about during that period. Or perhaps they might help their child select what s/he would like to listen to on a tape recorder.

5. It is important for parents and staff to accept the child's feelings, worries, and concerns.

It is not helpful to ignore the child's feelings, or to tell the child that s/he has no basis for the feelings, or to deny the child's feelings. Accepting the feelings gives the child more than reassurance. To be told only "don't worry," "you can do it," "it's not so bad," or "you're brave" is not as helpful to most children as giving information related to the current situation. Reassurance used with other techniques (such as information or suggestions for coping strategies) can aid the child in adapting to the stress. The child's objections, cries or fussiness during a painful procedure are probably stressful for the parents to hear, but are generally accepted as a child's right, and should not be criticized.

6. While parents wait with their child in the clinic/hospital for a procedure, distraction may help the time to pass.

Sometimes parents find it easier to talk about nonmedical topics and activities, unless, of course, the child wants to talk about the procedure.

There should be alternative activities available such as puppets, crayons, books, and puzzles, especially if the waiting period is expected to be long.

7. Parents can help their child to use books, dolls, and toys both to prepare for the experience and to relive the experience after the procedure.

All of these materials can assist the child in being informed and in mastering the situation. Parents can help by reading the child books about hospitalizations, and procedures. Some books that may be useful for preparation and for discussions after the experiences are A Hospital Story Stein, Becky's Story by D. Baznik, and The Hospital Book by J. Howe.

Some parents bring a camera to the hospital to take pictures of the hospital staff and places the child chooses. At home the child can remember and talk about, if s/he wants to, what happened there, and how s/he felt.

9. Even if a child has had the very same procedure before, s/he may need to be prepared again, and to be given time to talk it over. The child should be given a chance to play through what it was like for him/her and what it may be like again. Being older may make it easier, or perhaps more difficult; each child is different.

10. Sometimes children blame themselves for their illness and think that the treatment/procedures and the pain are punishment for being

bad. If parents are aware of this tendency, they can be extra careful to help their child avoid these feelings of guilt.

In general, the medical procedures a child undergoes are stressful for the parents as well as the child. Parents who can be supportive to their children throughout the experience however, tend to feel that they have made it easier for their children as well as themselves.

Pamphlet in press UCLA 1987

# Development in the Hospitalized Infant and Child

Nancy Brill, M.D.

Parents have many questions about how illness and hospitalization affect their child's development. Often they ask for guidance in handling problems. Development means a great deal more than the attainments of milestones. For every child it includes both cognitive (understanding, language, motor skills) and emotional (attachment, independence, socialization) issues. The stress of illness and hospitalization makes emotional issues particularly important for these children. The following discussion focuses on the most common questions parents ask. The ideas presented form a starting point for further discussion with the medical staff and the child development staff.

## Language

"Since coming into the hospital, she hasn't learned any new words. She may have even forgotten the words she had."

A child's language usage is quickly affected by the hospital environment. A baby or toddler whose language is just emerging may not feel safe and secure enough to continue to try new words. Language use

of even well known words by a hospitalized child is usually less than at home. Parents sometimes worry that this will be a permanent problem. This is not the case. Language acquisition in children occurs over a long time. The pause in either the use or acquisition of words that occurs with hospitalization is temporary. Knowing this makes it easier for parents to accept.

Some strategies parents use to be helpful to their children during this period include reading to and singing to their child, naming objects in books or the environment, calmly talking about what's going on around the child, naming hospital personnel, labeling the child's emotions, and letting the child know what's happening next. In many ways a parent can speak for a child until the child is ready to do it again for himself. His language development is certainly continuing during this time. It's not important that the child speak and he should not be pressured to do so. Although language is usually the developmental area where the sick child is furthest behind, it is also the area where the most rapid gains are made once the child is feeling better.

Gross Motor Skills:

"He's not walking as soon as I expected. Will he catch up?"

Both hospitalization and chronic illness affect this area of development. An infant or child who is sick does not have a great deal

of energy to use for motor activity. Sometimes growth and nutrition are not optimal and the infant may be small for his age. Often an infant must be left on his back in an infant seat or in a bed for long periods of time while undergoing treatments. This provides little opportunity for exercise and development of the trunk and neck muscles that occurs when the infant can spend time on his stomach. The creeping and sitting that follows, as arms and legs grow strong and balance is gained, is often delayed. The sequence of practicing weight bearing on bouncing legs with hands held, pulling to stand, cruising, and walking independently happens later then expected. Babies who are weak often devise their own ways of moving around, such as scooting on their backs or rolling over and over.

Although motor skills like language skills, often lag far behind in normal chronically ill infants, attainment of milestones on time is not so important. They will come very rapidly once the infant is in a better state of health. Any encouragement of gross motor skills has to be approached carefully with a sick baby, since to overtax him would not be helpful. Parents have good instincts about what their baby needs and can provide opportunities for gross motor development. When the infant is rested parents can change their infant's positions, giving him a chance to be on his stomach as well as his back. Attractive toys can be strategically placed as an incentive to move. Facing in different directions will give him varied views. Exercise games such as pulling to sit, or stand, bouncing baby on his legs, holding an object to one side to encourage reaching, rolling, and turning, and flexing and

extending arms and legs can be easily played in the crib and can be fun for both parents and baby.

Older chronically ill children too will sometimes lag behind in their motor skillss As with infants, weakness, feeling sick, and a lack of opportunity all have something to do with this. When the child begins to feel better, he'll begin to try new activities. It's sometimes difficult for parents to watch a child who's been through a serious illness race down the sidewalk on a tricycle. Watching him run, jump and climb (all risky activities) provoke feelings of fear and the need to protect in parents. But allowing these children to acquire these skills within safe boundaries is very important from the standpoint of physical strength and the child's sense of competency.

Attachment

"Won't it spoil him if we stay with him the whole time he's in the hospital. He cries everytime I walk out of the room."

Often parents fear that spending a great deal of time in the hospital with their sick child will make him demanding and difficult when he returns home. They may look at their hospitalized child, noting his reluctance to let them out of his sight and wonder whether they should put up with this behavior.

The demands of the sick child to have his parents with him during a hospital stay are signs of a healthy attachment to his parents, a firm trust that his parents have his best interests at heart, and a correct perception that a hospital is a frightening place where strangers do unpredictable, unexplainable, and painful things to children. In the child's eyes, and in fact, parents are both protectors and advocates for the child. This is a time when children really need their parents. Children will cope well with the hospital experience if they see their parents coping well. During the hospitalization parents can work with the hospital staff to provide the best care available for their child. While the staff focuses on medical treatment, parents can help with caretaking activities. This will make the child feel more "at home." Knowing their child's habits and moods, parents can help smooth difficult times.

A child will be more likely to come through a hospital experience emotionally healthy, if their parents have been able to stay. Behavior changes are common at home after discharge. A child may cry or whine more easily, may not want to be left alone, and may have changes in eating and sleeping patterns. These are normal changes and are not a result of too much attention in the hospital. Reassurance and patience will be helpful to your child as he regains some of the trust and confidence he had earlier and these problematic behaviors will subside.

"I know that my child would like me to stay in the room when she has her blood drawn, but I'm afraid if I do, she'll think I've let her down because I haven't stopped it from happening."

Parents often have this fear feeling that the child will think they are in collusion with the medical staff as painful procedures are carried out. This in fact is not the case. Infants and children need their parents at this stressful time. They need the comfort and reassurance and will remember that the parent was there for them. Parents can make it clear to both staff and the child that they are there to help the child and not to help with the procedure itself. Sometimes parents find it too stressful to be present for a procedure. Then someone in the medical staff or Child Development services can act in the comforting role.

Independence

"When should I let him feed himself? I know he could do it, but he has such a poor appetite."

Often hospitalized or chronically ill children are delayed in learning to feed themselves. Many of them have not been able to feed orally because of special medical needs. If they can feed orally, often parents and staff feed them far past the time when self feeding usually begins. Bottle feeding or breast feeding is often prolonged since appetites may be poor and the comfort of sucking makes this experience more successful. Sick infants have the same needs to become independent and competent as their healthier peers. Including them actively in the

feeding experience as soon as they are medically able, and begin to show an interest, is important.

Finger feeding with crackers or cookies is usually the first step. An older child who hasn't tasted solid foods may be much more resistant to textures, new tastes, and lumps than the 6-8 month old. He may mouth the foods and refuse to swallow them for some time. Parents may want to place a variety of finger foods on the child's tray and try not to be too concerned about what happens to it. It will provide an opportunity to practice the finger thumb grasp, explore with the lips and tongue, and practice releasing it into the mouth or onto the floor - all worthwhile activities. Since children love to imitate and please, sharing the mealtime experience with the family is important even if nothing is consumed at first. Tea parties that provide the opportunity to feed stuffed animals and dolls or to eat with other children the same age encourage self feeding as well. Self feeding with a spoon comes somewhat later than finger feeding but should be incorporated into the play of the older finger feeding child.

Sometimes a parent's fears that a child will not feed himself enough interferes with allowing the child to develop independent skills. Self feeding is messy and takes much longer. Schedules may need to be reorganized so that more time can be allowed for feeding. Creative ideas regarding calorie rich finger foods need to be devised. Given control over her own feeding, however the emerging toddler will usually increase her total intake. Emotionally the child benefits a great deal from the pride of accomplishment.

"She used to be so good but now she's refusing to let us give her medicine."

When a child who needs a great deal of care begins to develop independence, the caretaking may be more difficult. But this is a sign of normal emotional growth and an opportunity to facilitate the child's emerging independence. Refusal to take medication often occurs at the same time as insistence on self feeding. It presents a more difficult problem since this is an area where parents have to remain in control, but need the child's cooperation. Setting up a play situation with dolls or stuffed animals, pretend medicine, spoons and syringes will give the child a chance to enact some of his ideas and feelings about taking medicine. She may suggest in her play the best ways to do it or talk about the times she needs the most help. Older children may be given limited choices regarding the form of the medication or when it's taken. Sometimes they refuse to let a parent give it, but are quite willing to take it themselves. Since exercising control over important things in her life is a developmental task of early childhood, opportunity for choice and control should be created in other areas during playtime and other activities.

"It's past time for toilet training but he's going to have surgery next month. Should we start?"

Toilet training is an important accomplishment for every child. "When" it happens is not as important as "how" it happens. "When" may

sometimes be later for the hospitalized or chronically ill child. Before a child is toilet trained he must be able to recognize his bodily sensations and have sphincter control sufficient to allow him to wait. He must be skilled in walking, sitting, and getting up and down. And he must be interested in using the potty. A number of problems can delay this process for the chronically ill child. Gross motor delay, delay in sphincter control, and just not feeling well enough to be interested are problems. Hospitalizations too might interfere since the child is away from his usual routine and his own potty. Parents need not be concerned if toilet training happens on time but rather should wait until their child is ready and unencumbered by an upcoming hospitalization. Then the task can be approached as a new independent skill to be mastered by the child at his own pace.

## Socialization

"I would like him to play with other children but he's smaller than they are, and I'm afraid he'll get hurt or catch something."

This is a difficult decision for the parent of a chronically ill or hospitalized preschooler. There is a risk to children's play especially for a child with limited experience, small size, and a compromised immune system. The risks have to be weighed and discussed with your doctor. But parents also have to consider the benefits. Learning to be socially competent (to give and take, to share, to play by rules) to be physically skilled, and to grow cognitively are major

goals accomplished in play with other children. Settings may have to be limited and carefully selected in avoid undue exposure - but integrating the chronically ill child into a play setting is worth working for.

## Regression

"She used to be toilet trained, able to dress herself, and let us know exactly what she wanted. Since her surgery she is back in diapers and whines all the time."

This happens quite commonly after surgery or a traumatic hospitalization. A young child is emotionally overwhelmed by the events that have occurred. It's important for parents to know that this is a temporary change and that for a short time the child really cannot maintain independent skills even though he would like to do so. The child may need to go back into diapers, may want to be fed, may even want a bottle, and may want to be held for long hours. Some children stop speaking, or use baby talk. It is not helpful to insist that the child function independently "(if you want it you'll have to ask)" to be punitive "(you can't go to the playroom unless you use the potty)", or to point out the child's behavior "(you're acting like a baby)". Accepting the child's behavior and acquiescing to his needs will help her recuperate emotionally and actually hasten recovery of skills. If a child is witholding language, for instance, parents can let a child point at what he wants if she is willing. Some parents have even made up a picture board with familiar items and let the child communicate

this way for a while. Bottles and diapers can be used for a brief time with the certain expectation that they will soon be tossed aside. Gentle encouragement of the child's attempts to regain independence will reinforce her efforts and help her along.

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